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ABSTRACT

Described is the National Advocacy Project of the United Cerebral Palsy Association involving demonstration projects and model programs advocating the legal and human rights of the person with a developmental disability and his family. Goals and objectives of the project are listed as follows: improving the effectiveness of agencies and services to disabled children and adults; involving community residents; training and educating professionals, community residents, and consumers in the advocacy approach; identifying and testing advocacy approaches leading to necessary legislation; self-evaluation of the effectiveness of each project model and its components; disseminating the results of the project; and promoting replication of successful models, components, and techniques. Descriptions of project model sites in New York State, San Mateo and Santa Clara Counties, and Milwaukee; and replication sites in Greater Kansas City, Rhode Island, and Illinois are given. Problems and ways to involve consumers are discussed, and guidelines for program development are provided. Appendixes include advocacy model goals and objectives, copies of pamphlets, a list of legal issues, and a list of resource materials. (IM)

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thinking/learning/doing ADVOCACY

a Report on the National Advocacy Project of United Cerebral Palsy Associations, Inc.

Compiled by
Irving R. Dickman

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FOREWORD

In a search for needed services, United Cerebral Palsy Associations, Inc. was conceived out of compassion for children with cerebral palsy and their families some 25 years ago. By coordinating the efforts of volunteers and professional people, UCPA moved rapidly on to establishing a competence in demonstrating that those needed services could be developed. And, with the advent of "advocacy", we now have an enlightened point of view based on fact and skill. We have now learned that the key to improving our effectiveness in assuring that services are there at the time of need is *advocacy*—the component of service that makes the other systems work and enhances all of our other agency roles.

We have learned that advocacy does not just happen without a planned effort. Advocacy provides an opportunity to lead the way in changing attitudes and myths about children and adults who are disabled, as well as to improve the effectiveness of agencies serving the disabled and to develop new resources of service through a planned effort.

To learn how to be an advocate or change agent takes skill. We find out what people with developmental disabilities and their families need by encouraging their participation in all planning efforts. We design the strategies to bring this participation about. We establish a trust relationship, we identify barriers to the service delivery system, and move on to impact positively on the destinies of persons with cerebral palsy and other developmental disabilities utilizing their input.

The UCP National Advocacy Project described in this report has shown that if we are committed to truly changing the systems to be more responsive to the needs of persons with developmental disabilities, we can develop the necessary skills.

It has been my great good fortune to have worked, and struggled, with many really concerned and dedicated people in the development of this project. My gratitude goes to the funding agencies that had faith in our capabilities, to our sensitive and capable National Project staff, to those who have been an integral part of the National Advocacy Advisory Council, and to our imaginative Project Model Site staff. Also to all of the many consumers and other volunteers who have given so much of their time and effort to enable us to prove that goals can be reached when we share a positive commitment to equality for all persons with developmental disabilities and have the determination to overcome the barriers surrounding their lives.

I trust those who read this booklet will share the excitement of advocacy as we see it.

Margaret O. Murray, Chairman
National Advocacy Advisory
Council, UCPA, Inc.

What's The Word
A GLOSSARY OF TERMS

Advocacy: The act or process of defending or maintaining a cause; the act or process of supporting a cause. United Cerebral Palsy Associations, Inc., defines Advocacy as ensuring to persons who are disabled their rights to appropriate services.

Case Advocacy: Defending, maintaining or supporting the cause of one person; defending the rights of one person.

Class Advocacy: Defending, maintaining or supporting a cause on behalf of all persons having an identical problem or need.

Change Agent(s): A person or group of persons working to bring about desired change in laws, policies, practices or procedures so that the rights or entitlements of a person are insured.

Consumer: One who uses services; a person with cerebral palsy and his family; persons with a developmental disability and parents of children with developmental disabilities.

Components: A part of the whole; a process or procedure that has its own identity while maintaining its function within the project.

Case Manager: One who assists another individual in information, referral, follow-along services and serves as an advocate when there are barriers in receiving needed services; a person who is responsible for the implementation of a client's individual program plan by providing or obtaining needed services; a case worker.

Ombudsman: One who acts as an advocate for a person by receiving a grievance and investigating, interceeding or initiating action on this person's behalf.

Project Site: The geographic location of the UCP affiliate participating in the national project.

Model Site: The geographic location of the UCP affiliate participating in the national project and responsible for developing and implementing an exemplary program.

Replication Site: The geographic location of the UCP affiliates responsible for participating in the national project and closely reproducing the activities and results first enacted by the model site.

Model Program: A program serving as or capable of serving as a pattern of service that can be replicated or copied by others.

Program Development: Establishing a service or program to meet unmet needs.

Program Brokerage: A process by which it is necessary to act as an intermediary or negotiator among various parties when there is difficulty in establishing needed programs.

Organizational Advocacy: A social action program conducted by an agency or organization in which the agency acts to support and safeguard the rights and interests of persons having special needs.

Systems Advocacy: The act of changing a system that delivers services so that the services are more accessible, meaningful or usable.

Systems Analysis: The act of studying service systems for determining the nature and relationship of the parts of the system; the act of getting information about service delivery so that consumers or their advocates can determine what or where the changes are needed.

Support System: An organized group or persons promoting the interest of or upholding the rights of persons whose interests and rights have been violated.

I. INTRODUCTION

A Way To Think

The way advocacy started out, it meant acting on behalf of someone who couldn't do something for himself. Speaking, defending, protecting. The knight-errant was technically an advocate; the attorney is, by profession.

But anyone can be an advocate for people with disabilities. Parents are almost always the first; then relatives and friends; professionals—doctors, social workers, counselors, teachers, lawyers; volunteers and the staff members of voluntary agencies and the agencies themselves.

"For United Cerebral Palsy Associations, Inc., advocacy means that someone takes responsibility for seeing that the legal and human rights of the person with a developmental disability and his family are met. This includes the rights to education, property, community services, employment, social involvement and other necessities of life, as well as medical and therapeutic care . . . Advocacy concepts were first outlined in the IHF Plan (The Individual with Cerebral Palsy and His Family), developed by UCPA, in 1968."

This description was prepared by Marie L. Moore, UCPA, national advocacy coordinator. It details what UCPA's President, Warren F. Beer, has listed as one of UCP's four primary goals: "To engage in a positive advocacy relationship with handicapped persons."

The Implications of Advocacy

Or, as UCPA's executive vice-president and chairman of the National Advocacy Advisory Council, Margaret O. Murray, said: "The message of the IHF Plan, which led to the development of our Advocacy Project, explicitly declares that the role of UCP is shifting from that of a provider of services to that of a catalyst—one who stimulates others to serve, one who advocates."

Ask, and you quickly discover that advocacy has *many* meanings, many implications, even under the UCP umbrella.

Edwin Minter, executive director of UCP of Greater Kansas City, is one of those participating in the National Advocacy Project. He says: "In trying to define advocacy, a lot of things come quickly to mind—helping, helping someone; change, change what? The 'and/or' system—system implies getting in or getting out, or both. If it's a system, someone needs to analyze it. After having spat all this out, I'll give you a word. Advocacy means helping . . . by being aware."

To Robert Schonhorn, UCP executive in New York State, another advocacy site: "It's finding the people. It's finding out from them what services they need. It's protecting their rights with

governments, making sure they get the things they deserve to have, that they're not frightened, that services are available . . ."

Jane Chapin, Illinois UCP executive, a third site, says: "Advocacy to me means any activity of a person or agency on behalf of another person or group of persons designed to protect or enlarge the individual's rights and privileges. Advocacy can be attempted by exhortation, by legislation, by litigation, or anything in between."

Advocacy has many meanings. One of the purposes of the UCPA national project was to attempt to provide a pragmatic definition, specifically for people with cerebral palsy and other developmental disabilities. Additional meanings were therefore bound to emerge from those most deeply involved in the project.

In October 1975, a workshop in San Francisco brought together UCP officers and volunteers, national staff members, and the project site advocacy coordinators to share their experiences and their expertise. Here are some descriptions excerpted from their comments:

Teresa Smith, advocacy coordinator, Rhode Island: An advocate is someone who speaks up on behalf of an aggrieved person to a decision maker, to seek a remedy. He presents evidence, uses whatever persuasion he can.

Georgeann Chaffee, advocacy coordinator, Kansas City: One of the first processes involved is establishing a trust relationship between the affiliate and consumers—parents and disabled adults both.

Ernest Weinrich, UCPA national project director: Advocacy is a systematic approach to helping people get the kind of help they need.

Dr. Mildred Erickson, member of the National Advocacy Advisory Council and community organization consultant: The role of the advocate is to keep his or her focus on helping groups to become self-advocates.

Smith: The advocate must be constantly oriented to working himself out of a job, knowing that what he's been trying to do, what he has started, will then go on without him.

Weinrich: For advocacy to work, the commitment of the affiliate to advocacy has to be there.

Robert Hansen, advocacy coordinator, San Mateo-Santa Clara: A lot of organizations which advertise that they're "doing advocacy," are really pushing organizational clout, a form of paternalism, disguised as advocacy.

Weinrich: We have to be careful that advocacy doesn't become the same as everything else. We cannot go away saying this is something we've been doing all along . . . Advocacy is a conscious process, a conscious act. If the host agency supports it, it is because the agency wants change . . . to achieve the agency's goals more quickly, to make the system more responsive to the needs of the people . . . Each of us in the Advocacy Project—anyone who is wont to call himself an advocate—is a change agent. All our data collecting, all of our systems analysis is related to change within our community, within our society, and even within our own organization.

John Siepp, educational consultant, UCPA: It is clear that advocacy is really another way to think. People need time to absorb it. It's not easy. It's a different way to approach the system.

John Butler, director of field services, UCPA: If the affiliate isn't ready for advocacy, it is not going to adopt it as an approach.

Margaret Murray: If the affiliate isn't ready for advocacy, we have to help it get ready.

How and what the UCPA National Advocacy Project has contributed and is still contributing to help UCP affiliates "get ready" is the essence of this report. It is information, a distillation of experience, some tentative conclusions, an examination of some of the implications of the advocacy approach—for affiliates, for the community, for consumers.

For if advocacy is "a way to think," it requires some thinking about. As a conscious process.

And if advocating is "a way to do," it is worth learning to do well.

Even if there are those who feel that advocacy is what UCP has been doing all along. That advocating is what UCP and other volunteer organizations are born to do.

Why A Demonstration Project?

In the past decade, voices have increasingly been heard—including those of the 1970 White House Conference on Children—urging the advocacy approach as the quickest and most likely method of improving the delivery of services to disabled children and adults—of reforming or changing the "system." In 1971, three agencies of the United States Department of Health, Education, and Welfare jointly undertook to fund a serious exploration of the processes involved in advocacy. The agencies—the Bureau of Education for the Handicapped of the Office of Education, the National Institute of Mental Health, and the Developmental Disabilities Office—provided funds to six community groups. In 1972, two state agencies and three national organizations, including United Cerebral Palsy Associations, Inc., were selected for demonstration projects varying in geography and environments and incoporating a variety of components, objectives and processes.

While encouraging maximum flexibility, initiative and ingenuity on the part of organizational and other sponsors, the three H.E.W. agencies did set certain goals and objectives for each of the demonstration projects:

- Improving the effectiveness of agencies and services to disabled children and adults;
- Involving community residents;
- Training and educating professionals, community residents and consumers (disabled people and their families) in the advocacy approach;
- Identifying and testing advocacy approaches leading to necessary legislation;
- Self-evaluation of the effectiveness of each project model and its components;
- Disseminating the results of the projects to increase the awareness of the community, and perhaps to develop local financial support for continuing the program after federal funds run out; and
- Promoting replication of successful models, components and techniques.

As a result of the projects' built-in monitoring mechanisms, both internal and external, by 1973 Ethel D. Dalmat, who had major responsiblity for coordinating N.I.M.H. participation in the three-agency arrangement, was able to cite difficulties in transferring major project efforts from case advocacy to class advocacy, and in measuring the impact of the projects as agents of social change.

But there were also some notably positive aspects. "The strongest element in the projects, without exception," Ms. Dalmat reported, "has been the advocates on the front lines in direct contact with the community. Through the training they have received and their experience in the field, coupled with their dedication and excellent motivation, they have become a disciplined force for positive change in their communities."

Of course, some of these advocates, like the advocacy coordinators in the UCP affiliates' models, were trained professionals. But by and large, Ms. Dalmat noted, "the advocates associated with the various projects are themselves members of the target communities. Through their efforts in the projects, they have discovered that they need not feel hopeless or helpless as before, but that they could impact positively on their destiny, using appropriate advocacy methods."

For UCPA — An Opportunity

The possibility of sharing in the national advocacy demonstration was for UCPA not only an opportunity to implement one of the major goals of the IHF Plan, but in a way a return to the original vision of UCP's founders, who were in effect practicing advocacy. Among the objectives of the founders were several which today are very much a part of the advocacy approach: "To cooperate with governmental and private agencies concerned with the welfare of the physically handicapped;" to provide information "to all persons concerned in the care of, rehabilitation, education and employment of the cerebral palsied;" and especially "to promote a normal outlook for the cerebral palsied."

UCPA's National Advocacy Project was launched in July 1972, with a view not only to immediate experience, but to future replication by the approximately 300 UCP affiliates and other groups serving the developmentally disabled. The three demonstration sites were selected for their differences in: a) populations—a variety of socio-economic and racial-cultural groups; b) geography—across the country, and to include rural, suburban and urban locations; c) levels of government; d) patterns of service availability and delivery; e) organizational patterns and programs.

The models were also to differ in the advocacy systems to be tested. The New York State model was to explore case management advocacy, systems reform, program brokerage and consumer action. The San Mateo-Santa Clara Counties (California) model, was to test advocacy through activities in community organization, program development, and consumer group participation. Milwaukee was to investigate the private case advocate approach, community organization, program brokerage and systems reform. Integral to all the models were such processes as systems analysis and data collection, which were also to be evaluated.

As specific operational goals, the project was to assist consumers in obtaining needed services and to improve service delivery systems. But it was the third objective which was decisive. This focused not only on what was to be accomplished, but on how "to increase the advocacy role of consumers (individuals with developmental disabilities and their families) through their participation at all levels of planning, policy-making and monitoring of UCPA activities and programs."

In incorporating one of the IHF Plan's long range purposes—to lessen the dependency of the disabled person and his family on others—the Advocacy Project deliberately omitted such types of

advocacy systems as citizen advocacy, the public case advocate and mandated protective services. Paradoxically, these systems, all designed to provide essential assistance to the person with disabilities, are structured to act for him and not to foster his advance toward independent action.

UCPA's Role

The responsibility for setting objectives for the UCPA National Advocacy Project, for establishing national guidelines and priorities, for providing overall leadership to affiliates and to individual staff people, was vested in an autonomous National Advocacy Advisory Council (NAAC), half of whose members were themselves consumers. Margaret O. Murray is chairman of the council; she is also UCPA executive vice president and therefore a link between the Council and the UCPA corporate body.

Each advocacy project site has its own Advocacy Advisory Council, state or local, with responsibilities basically similar to those of the NAAC. Organizationally the links are strengthened by the fact that one representative from each site serves on the National Council.

A seven-point program of activities, emphasizing increased consumer involvement, was spelled out in an NAAC statement, "Strengthening the Partnership Between Consumers and UCPA," which was adopted by the UCPA Executive Committee in September 1974. (See Appendix A for the full statement.)

What Chairman Murray saw as the first step in increasing consumer involvement was "setting an environment . . . a dissemination of facts from Advocacy Project sites that consumers are capable of being contributing members of decision making bodies . . . We must understand how the disabled and their families can be a resource to UCPA, and how such a partnership can enhance the effectiveness of the organization in many ways."

To see how the UCPA structure was to be involved in "setting an environment," it is worth quoting from a background memo issued early in 1975 by UCPA Executive Director Earl H. Cunerd:

"One hears a great deal about consumerism these days in all fields of endeavor, and our organization is no exception. As the children UCP set out to serve 25 years ago have grown into adulthood and as their ranks have been multiplied by many other disabled individuals . . . it has been only natural that consumers would be propelled into the programs and activities of UCP.

"Over the past few years both National and many affiliates have moved forthrightly to involve consumers in the association. We have strengthened UCP's advocacy role by encouraging self-advocacy on the part of the disabled, and one-to-one responsibility for the handicapped by more able-bodied persons. We have remodeled UCP programs and services to meet the growing and changing needs of our adult clients, encouraged clients to serve on our boards and employed persons to work in our programs.

"But have we done enough? Are we thinking ahead to new and innovative ways to bring UCP consumers into full partnership with our service providers? And whom do we consider to be our consumers—the young person or adult with cerebral palsy alone, or together with his or her parents and family? Or do we add the traditional 'consumer groups' in our overall community structures, the racial and class groups, youth and the aging, the ethnic and religious groups, the lower as well as the middle and upper socio-economic strata of our communities?"

Other NAAC Responsibilities

Three other program proposals were submitted by the NAAC. A proposal for early identification and referral of infants and children with developmental disabilities was adopted by the UCP Executive Committee. On another matter, the bylaws of the organization were amended in 1975 to establish a Legal Advocacy Committee (see Appendix B). And a proposal to urge employers to provide time off with pay to volunteers now excluded from service on boards and committees because they cannot afford the monetary loss (see Appendix C), was adopted by the Executive Committee, but not accepted as policy by UCPA's corporate body.

The NAAC has also exercised a number of other leadership responsiblities. It has, for example, supported the establishment of a national consumer caucus, out of which thereafter evolved the Consumer Activities Committee of UCPA, a standing committee staffed by a person with cerebral palsy.

For the Advocacy Project, the NAAC has determined policies and priorities and been responsible for monitoring and evaluation, as mandated by the funding agencies. Because of this latter function, UCPA is looking to the National Advocacy Project, ultimately to find out which processes and components of advocacy can be used by some 300 nonproject affiliates to further their advocacy roles.

Demonstration sites were therefore asked to report quarterly, both on their progress toward their long range goals and on specific intermediate objectives as well. In addition, site visit teams made on-the-spot surveys of the impact of the project and the effectiveness of its advocacy council and coordinator. They looked at the development of support systems and of advocacy processes generally and how effective each has proven to be, and cast a critical eye at the degree to which consumers have been participating in each model.

To help the NAAC and the funding agencies to make their evaluation, the site visit team reports provided not only a description of the model and its accomplishments or inadequacies, but a picture of the host affiliate and its community. Through extensive interviews, the teams also conveyed the perceptions of the model and of advocacy held by affiliate volunteers, leaders and staff, lay and professional leaders in the community, members of the Local Advocacy Advisory Council (LAAC), the advocacy coordinator, and the sometimes-forgotten consumer.

The reports and other incoming materials were esteemed as a valuable feedback which gave the NAAC and the national project staff something like a moving picture of the projects, rather than a series of still photographs. Their estimates could therefore be based on what actually was happening rather than on what was supposed to be happening.

Even for the most pragmatic observers the projects provided some surprises.

II. PROJECT MODEL SITES

New York State

For demonstration purposes, New York is not only the second most populated state, but offers a wide variety of socio-economic and geographic variables. The state's 22 UCP affiliates are located in urban, suburban and rural areas. They serve some 45,000 developmentally disabled people and their families. Unaffiliated areas are chiefly rural, with few if any community services, but the state UCP organization has a history of successful program development in unaffiliated areas.

A major factor in the choice of New York for the advocacy project was that the state affiliate is strong, with a well-structured administration and an experienced, knowledgeable staff. Its recent activities have emphasized legislative and governmental efforts and improved community and professional services such as a statewide home service program.

The model developed by the state had four major components:

1) Increasing the affiliate's impact on legislation;

2) Initiating, expanding and improving programs and services, with priority for rural areas and people in state institutions;

3) Expanding the activity of consumer advocacy groups; and

4) Increasing the advocacy role of the 15 UCP home service directors.

While this was the envisioned order of priorities, the role of the home service directors was actually to be a much more active and far reaching one. Largely through them, the advocacy approach was to be integrated into affiliate activities. It was they who would have major responsibilitiy for increasing consumer participation and for working with families whose children were in state institutions, and directly with the institutions themselves.

The first objective of the New York model (see Appendix D) was: to prepare legislative proposals and to promote legislation to meet the needs of the developmentally disabled people of the state.

Through the advocacy approach, legislative efforts, which had been resting largely on the shoulders of the affiliate's executive director, achieved considerable consumer input. The executive, Bob Schonhorn, estimates that 40-50% of the legislation eventually recommended by the state board of directors was initiated by consumers through the State Advocacy Advisory Council (SAAC). Specific laws were drafted. In 1974 alone, five key bills were passed as a result of this process. They bespoke the affiliate's increased leadership in this field.

But the new laws were only the end product of an extensive legislative monitoring system and a consumer education program aimed at increasing their fund of information and at also raising their level of political and legislative sophistication. In the process, consumers, volunteers and staff all developed and matured.

Not only did the affiliate detail the step-by-step process from an idea to state law; it tracked specific bills through this process and alerted local groups to act and to apply pressure locally at the right time. This Bob Schonhorn considered the most effective kind of activity on statewide issues. One state senator, though unaware of the Advocacy Project, told the site visit team that he had noticed more people in wheelchairs appearing as witnesses at legislative hearings and considered them an effective force in persuading legislators.

Second among the New York priorities was to improve existing programs and to create new ones for disabled people, specifically in rural areas, and to work with four state institutions, both to upgrade their programs and to help some of their residents emigrate to communities and the world outside.

Such new programs and services have in fact been initiated in some of the nonaffiliated northern rural counties of the state, including an evaluation clinic and a preschool program. This often involved the former state advocacy coordinator, Lynn McMillen, in community organization processes as she worked with other agencies in surveying needs and available resources. In two counties, she followed up the surveys by helping local affiliates contract for needed services.

To help improve the quality of institutional care, the coordinator joined with other staff members in producing a training manual for direct care personnel. In aiding people to leave institutions, she helped to establish a hostel in Buffalo, which was seen by the staff as the "liberation of the consumers." Three more such community residences are planned.

Another major objective of the New York project was to involve consumers—disabled adults or parents or both—in planning, policy making and monitoring services on both state and local levels and in improving service delivery systems. Both individual consumer participation and local consumer advisory and action groups were to be encouraged.

The consumer contribution to the state's legislative program has led Bob Schonhorn to propose that there should be opportunities for consumers to impact on all UCP programs.

He cites action on complaints from disabled people in New York City that programs were being compartmentalized too much. As one man said, "I want to thank you for ripping me into little pieces. Every time I started to sit down in my classroom, somebody else came to take me away." Now, instead of disabled people leaving their classrooms to meet program staff, staff go to them.

In another example, at the Nina Eaton Center, the UCP residence on Staten Island for 50 ex-patients from the Willowbrook Developmental Center, psychologists and other staff personnel now work split shifts, if necesary, to provide coverage 12 hours a day, seven days a week. "Unheard of," says Schonhorn, "but the professionals went along with it. I guess nobody ever asked them before. And that's the result of the intervention of disabled people."

One of the most visible example of consumer participation is the state board of directors. Previously it had members who were disabled but ambulatory. Now the board includes people in wheelchairs as members-at-large. And it now meets only at barrier-free locations.

Local Consumer Groups

The present state advocacy coordinator, Libby Wickes, spends a considerable part of her time working closely with local consumer groups, passing on information and helping them exchange information with similar groups. A major problem she found in trying to show them how they could be more effective advocates, is that as consumers they have been treated as second-class citizens for so long they often fail to appreciate what they might be able to accomplish. With few participatory experiences, many have no real confidence in their ability to achieve results, produce changes, and make systems respond to their needs.

Though few in number still, the groups range from the far north of the state to Long Island. They differ in composition and lifestyle (a number of the most active members of the Geneva group communicate with lapboards). They differ in orientation (some "are not necessarily making local affiliates comfortable," comments Schonhorn). They differ in targets (one fights architectural barriers, another monitors education programs).

Buffalo's Advocacy-in-Action (AIA) group last summer took on the Buffalo Memorial Auditorium, which wanted to add new seats. This would have cut wheelchair space and limited accessibility. The result of their fight was three times more space for wheelchairs. AIA is "focusing on everyday problems of the individuals and how they relate to their families and the community," reports the local UCP executive. "In-depth discussions on architectural barriers at one session resulted in the group joining with the Geneva Handicapped Committee as advocates for building code changes. The willing cooperation (of the local congressman) has been enlisted in affecting local architectural changes."

Can't became can when, thanks to AIA's efforts, the Buffalo City Council voted that there must be cuts in all new curbs after July 1976.

Home Service Directors

In large measure the implementation and effectiveness of the advocacy coordinator's efforts depended on the cooperation and support of other state and local staff members, particularly the home service directors. One of the major objectives of the Advocacy Project, therefore, was to give home service director's additional training and technical assistance to increase their advocacy role.

In eight training sessions each year, the advocacy coordinator stressed the rights of the disabled and strategies to secure them, laws affecting delivery of services and problems in getting services, what federal, state and local agencies are supposed to do, and how to use them.

With the improvement of clinic-based services, and with less of their working time required for therapeutic intervention, many of the home service people have been able to increase their advocacy activities considerably since the project started. They have become more involved in community work and community organization, particularly in the areas of case finding, early intervention and placement, public and professional education, location and referral to existing programs, and development of new services.

The home service directors have also been able to set up a resource network among themselves, and an advocacy section has been added to the UCP home service reporting system. While their emphasis is on case advocacy, their success has stimulated intensified class advocacy on the part of local affiliates, as well as the state organization.

Wherever possible they seek consumer involvement. Worth noting is the system established by one director where parents provide direct aid to other parents traumatized by their youngsters' disabilities. Their "parents' support system" has two telephone hot-lines, one for mothers and one for fathers.

In their advocacy role, the home service directors feel that they have had considerable impact not only on their affiliates, but on the whole developmental disabilities system. They are convinced that the philosophy and suport of the state organization has helped them to promote program development in centers operated by local affiliates, even though they sometimes have met resistance from local administrators or boards. As their advocacy role expands and is recognized, more of them are being invited to serve on boards, councils and committees of other organizations. They are now accepted as representing the needs of the disabled consumer family in the community.

The state advocacy project, said one home service director, "opened our eyes to another side of services. Our role becomes larger every week."

In fact, advocacy is now seen as an additional dimension to home management functions, providing additional clues on how the home service director can help parents to plan for their disabled children, and disabled adults to plan for themselves.

What to Replicate?

For state affiliates with home service or similar programs, one of the processes of the New York State Advocacy Project, which ought to be considered for replication, is surely that by which the advocacy role of the home service directors, individually and collectively, was developed, strengthened, expanded.

There are also six other components of the New York model other states might want to consider:

- How the project was integrated into the ongoing operations of the state affiliate
- How local advocacy groups and councils were established
- How these contributed to the affiliate's state legislative activities
- How the advocacy program provided technical assistance to local affiliates for program development and expansion
- How programs were established in unaffiliated areas
- How disabled people were helped to leave institutions and move out into communities

A number of these components are already being put to the test, in conjunction with the National Advocacy Project. The state of Illinois has been selected as a replication site of the New York State model.

San Mateo-Santa Clara

For the investigation of the advocacy approach at the county level, the project choice was two California suburban districts, a sprawling population area including many residents with Spanish

surnames. What made it possible to treat the two areas as a single entity for demonstration purposes was that the separate UCP affiliates in San Mateo and Santa Clara counties are served by a single professional staff.

In both counties, services available to people with cerebral palsy and other developmental disabilities are surprisingly limited, particularly for California. San Mateo County has a number of public agencies serving the developmentally disabled, but they are considered inadequate for people with severe or multiple handicaps. Service delivery systems are dominated by public agency administrators and private physicians. In Santa Clara County, major services of the state supported regional center for the developmentally disabled have been provided almost exclusively to the mentally retarded because of the funding pattern.

Such a situation seemed made-to-order for the advocacy approach. It was hoped that the demonstration project would evoke a new responsiveness from service delivery systems and that involving "consumer power" would help the two UCP affiliates expand and improve services for disabled people.

The core concept of the model was to develop opportunities for consumer participation in policy making and in planning. In the view of the UCP executive director of San Mateo and Santa Clara Counties, the three years since the project was initiated have changed the affiliates' personalities, converting them from an orientation as service providers to activist organizations. In large part that is because the Advocacy Project's objectives, priorities and processes have been integrated into the total operations of the host agencies. The model was designed to make the organization as a whole a more viable change agent. The approach has enlisted staff support and impressed volunteers. The affiliate boards have now approved continued funding for the program.

Components of the Model

One of the model's components was the expansion of UCP's traditional case advocacy role in the community. The others were

- Systems analysis of services, programs and consumer groups for developing community organization approaches;
- Planning for case finding and outreach program development activities
- Development of forums or arenas for consumer interaction with service delivery and planning units.

In this latter connection, it might be noted that in San Mateo County the Coordinating Council for the Developmentally Disabled is both a planning body and a forum, thus permitting a certain amount of consumer participation. The Santa Clara Advisory Commission on the Developmentally Disabled, on the other hand, is largely controlled by service providers. It became a primary target for change by the Advocacy Project because, with the potential power it had to expand the service delivery system, its priorities did not comply with California's State Developmental Disabilities Plan.

To illustrate the difference between the two bodies in practice, in San Mateo parents who sought a state funded development center for handicapped minors were able to confront school administrators who, they felt, were not active or aggressive enough in pressing for the center. The result was an

officially accredited parents' advisory committee. By contrast, in Santa Clara County, the advocacy coordinator, Bob Hansen, notes, "there seemed to be no place for a group of aggrieved parents to take their grievance to, to be decided on its merits before a fair minded panel."

Why Systems Analysis?

Goal I of the model (see Appendix E) was "to identify, describe and assess the targeted programs provided by public and private agencies for the developmentally disabled." Goal II was "to describe and evaluate differences in and barriers to the utilization of services by families with children who are developmentally disabled." Goal III was "to identify services needed and/or changes sought in the service delivery system from the consumer's perspective."

While it was known that the needs of people with cerebral palsy and other developmental disabilities were not being adequately met in the two-county area, each provider had been so completely engaged in delivering his/her own specific service that none had had the time—let alone a mandate from employer or board—to examine the total "territory" or to advance the fragmented service system toward the long range goal of greater comprehensiveness, cooperation and general improvement of services.

The first and continuing effort of the advocacy coordinator, therefore, had to be directed toward an analysis of the various systems in operation. Working under priorities established by the Local Advocacy Advisory Council (LAAC), the coordinator collected information on the actual utilization of services in both counties, consumer concerns for improvement of services, opportunities for consumers to provide input into service agencies, and the political situation as reflected in the relationship between various power groups in the community relative to development of services.

Because this approach of basic systems analysis was new and crossed the hitherto rigid boundaries of specific agency and staff concerns, the coordinator came to be regarded to a great extent as a community organizer. To some degree this was inevitable. While he was assisting UCP and other case advocates by providing them with specific data, he also found himself called upon to suggest community organization strategies affecting class advocacy.

Service providers began to turn to the advocacy coordinator for current information on federal, state and local laws and regulations. In the process, the coordinator was able to identify professionals and other persons whose basic attitudes and philosophies about consumer access to service systems were similar to his. They soon became part of an informal support system for the coordinator, for each other, and for the advocacy approach. He needed such support, because he also encountered professionals, volunteers, and entire organizations that were determined to maintain established practices and relationships. To maintain their power? Because of ineptitude? Or simple inertia?

For data collection, the informal approach was usually more productive than an official request through channels. Learning the territory, he found that service systems, and therefore sources of information, differed considerably in the two counties. With considerable ingenuity, he explored hitherto untapped sources. For example, he found census tract maps (free from the county planning office) useful in locating persons with developmental disabilities. From these he prepared charts (see Appendices F & G) which he used as a conversation-starter with staff people, often opening the way to a fair exchange of data, information, and contacts.

Toward the end of the project's second year, the coordinator gained additional mileage from his collected information. He was instrumental in the publication of an information folder for consumers,

"Finding Help for a Disabled Child in Santa Clara County" (see Appendix H). While "the idea of a reference list so that parents might know whom to call for what services . . .is scarcely original," as the coordinator, Bob Hansen, points out, it did not up to then exist in Santa Clara County, perhaps because "some agencies seem reluctant to advertise their services even when the services are entitlements . . ." The leaflet was kept simple. ("Parents don't need to have all the updated information which a professional case worker or referral source has to have on hand.") To be sure it was simple, after each provider had described his own services a consumer mother was asked to rewrite the material. She not only took out all technical terms, but added a paragraph which began: "It is important to be persistent in your efforts to find the agencies and services that can be most helpful to you."

A Spanish version of the folder was also published (see Appendix I) since the coordinator had learned from readily available sources during his data gathering that 14.6 percent of the handicapped children served by county programs came from Spanish speaking homes.

The folder, comments Bob Hansen, "was a relatively simple organizational activity yielding a tangible product—a printed page parents can keep or share with other parents. It . . . provided consumers the names and addresses and telephone numbers of agencies to be asked for help." Systems analysis had thus helped consumers to learn what services existed and to gain access to the system.

Planning and Program Development

Though the primary goal of the San Mateo-Santa Clara project was to increase consumer participation in policy and planning decisions, there were occasions when parent advocacy for improvement of services exposed a gap in existing programs, thereby posing a dilemma for the advocacy coordinator. To quote UCP executive director John Huckstadt: "Once a need is defined and a program conceptualized, UCP as a community organization-minded agency has several options—a) start a UCP program to fill the need; b) get another agency or a coalition of agencies to fill the need; or c) get the consumers to work on it." In practice, the coordinator found himself pursuing all three options at one time or another.

One application of Option a) came in implementing a National Advocacy Advisory Council policy statement (see Appendix J), which had urged UCPA to intensify early identification and referral of infants and children with developmental disabilities. The statement focused on identifying the barriers to early identification and referral and urged an exploration of what could be done to eliminate them.

In Santa Clara County, the data which Bob Hansen had gleaned indicated some 30 children would be born each year in the county with cerebral palsy, but most would not be known to Santa Clara County Crippled Children's Services until they were four or five. Though many would be difficult to diagnose before 18 months, some would be known to private physicians. On the other hand, some families would have no access to professional assessment and would not understand their child had any anomaly or developmental delay.

Early Identification & Referral Project

In keeping with the NAAC proposal, a Santa Clara project was developed as a joint effort of the advocacy coordinator, who wrote the proposal, and the UCP Child Services Coordinator (see Appendix K). A $10,000 grant was obtained from the California Office of Developmental Disabilities.

Two half-time public health nurses employed by UCP spent six months contacting community agencies, hospitals and medical professionals, raising their consciousness regarding early referral and its value to children and parents. The participation of other agencies with UCP in the project's advisory committee significantly improved interagency links in other areas as well.

The project has enhanced the UCP affiliate's leadership role in the community, since UCP had taken the initiative in what became, in effect, an interagency project. It has also demonstrated the way in which the Advocacy Project blended smoothly into affiliate operations.

And it contributed to bridging the gap between providers of service and Spanish speaking consumers with a seminar (since repeated in San Mateo County) on "Services for Developmentally Disabled Children from a Chicano Perspective."

Project Impact

In the two-county area, it was to be expected that those consumers with least access to services would be members of the sizeable Chicano community. The language barrier, of course, complicated their lack of basic information about their rights and the services available, but there was an additional cultural factor. As Dolores Garcia points out, people in the Chicano community refer to someone with a disability as a "sick person" who will one day get better. There is therefore no need or no urgency to do something about him or for him.

Perhaps, she comments, that is why "most of us have been left behind by everybody else with regard to disabilities, and doing something about them." Ms. Garcia is herself a parent of a disabled child, a member of the Local Advocacy Advisory Council, a student and teacher of social work, and consultant to the San Mateo-Santa Clara Advocacy Project.

The first step in reaching out to parents and people with developmental disabilities in the Chicano community was to form a small group of parents knowledgeable and articulate enough to deal with agency staffs. An opportunity in this direction developed late in the summer of 1973, when the advocacy coordinator learned that the National Association for Retarded Citizens had secured OEO funds for "Project Impact," a neighborhood outreach to low income minority families with retarded children. Because of his widespread contacts and the expert knowledge of needs and resources, he had gained from data collection, the advocacy coordinator was able to convince the local ARC affiliates to apply for joint sponsorship of such a project. He prepared the proposal and supporting documentation and served afterward as a member of the advisory body. He was described by a parent in the Central Santa Clara ARC as the "driving force who tied everyone together."

East San José was chosen as the target area, and a community worker was hired to offer services to the Chicano community. To summarize its impact, while the project cannot be considered completely successful it did reduce language barriers notably. Notices from school are now in Spanish and parents volunteer to translate for Spanish speaking families with problems. In terms of increased consumer involvement, neighborhood parent groups have been organized, and school administrators have been meeting with the groups in their homes to discuss their concerns about problems in the schools.

Consumer Participation

This development was reflective of Goal IV of the advocacy project: "To strengthen and increase the paticipation of a diversity of consumer groups and individuals in the planning and delivery of services for developmentally disabled children and their families."

Perhaps the most notable of such groups was the one which had produced the Spanish information folder—the Chicano Perspectives Forum, organized with the aid of the project coordinator, where a committee of agency representatives met with Spanish speaking parents to discuss the needs of developmentally disabled people in the Chicano community.

But there were at least three other groups in which consumers came to play a major role. Within a month after the advocacy coordinator joined the UCP staff, the Local Advocacy Advisory Council (LAAC), composed of consumers and providers, met for the first time. It has been meeting regularly since, providing direction and support for both the coordinator and the project. Particularly during the first year, the group examined goals and methods and adopted policies and priorities. The fact that the coordinator was answerable to a group with known standing and commitment also provided assurance to the UCP executive director, who had confidence in the individual LAAC members and the group as a whole.

About a year and a half after the LAAC began to meet as a consumer-provider group, two of its members organized PICS (Parents for Improved Community Services) for activist parents of disabled children in Santa Clara County. From the outset, PICS deliberately excluded professional providers, although the advocacy coordinator was admitted as a guest observer. With the appearance of PICS, the LAAC began to concentrate more on policy formulation and less on implementation. (For more on PICS, see page 126.)

But the National Advocacy Project had undertaken to explore a variety of organizational forms through which consumers could voice their concerns and have an impact upon systems. Thus, while PICS deliberately excluded nonconsumers, the Santa Clara County Developmental Disabilities Forum just as deliberately brought consumers and providers together to discuss their mutual concern over inadequate services. Some 20-25 percent attending are consumers. "The monthly meetings," says the advocacy coordinator, "have on several occasions functioned as arenas for consumer advocacy. Parents can sit comfortably across the table from agency heads and line staff to speak their minds on service improvement."

Basically, the Forum was organized because the county Commission for the Developmentally Disabled reflected narrow concerns for the mentally retarded alone. The Forum now offers the best potential for changing the area's service delivery system. It has developed and submitted to the county commission a "counter-plan" which not only reflects the broad definition of developmental disabilities, but also complies with state guidelines on the subject.

It is worth noting that among those actively involved in the planning are 10 parents of disabled children who were strangers to the process until two years ago. Worth noting because consumer involvement was just as important a goal of the San Mateo-Santa Clara project as the specific changes effected in the service delivery system. And possibly with broader long range implications, if the best hope for a responsive system is a continuing accountability to the people it serves or should serve.

On the not-so-plus side, the advocacy coordinator has himself noted that most of the consumers participating in the project have been parents. In the coming months he will be giving more of his active attention to enlisting disabled adults on such priority problems as the removal of architectural barriers, transportation, residential and avocational opportunities.

Some Reactions

One thing about an advocacy project based on the San Mateo-Santa Clara model—it stirs people up. An approach deliberately designed to enhance community awareness of the nature and effect of

established practices leaves few neutrals among those involved in any way with disabled people.

To show how current practices interfere with making systems accessible to consumers in need is bound to raise the hackles of those with a vested interest in the status quo. And so those most negative about the project are primarily to be found in the established power structure. What they have said, to summarize, is that the advocacy approach is "confusing many of the young parents who have so many problems at home" and who are not "ready to be their own advocates." What they mean, of course, is that the parents should let professionals be their advocates. Or, why bother with advocacy at all?

Even some parents have been critical. The advocacy coordinator has been accused of insensitivity to the needs of the mentally retarded for improved and expanded state institutions and residential facilities, rather than community-based services for all of the developmentally disabled. After all, goes the argument, shouldn't an advocacy project serve all?

The answer, of course, is a matter of emphasis and priority. On the positive side, many professionals who have had to deal with the same environment feel that the advocacy coordinator, as an outsider, could say what they could not, working in established programs. They have hailed the project for facilitating cooperative planning and for channeling the anger of parents into productive activity. UCP staff members are not the only ones who feel that parents can sometimes be more effective advocates than professionals.

In essence, the advocacy project approach has enhanced UCP's long range role as a systems change agent—to make the system serve more people . . . better.

Components for Replication

The complexity and relative sophistication of the San Mateo-Santa Clara advocacy model would argue that UCP affiliates thinking of replicating it should share some of the characteristics of the two California affiliates and their environment. Among these are staffing pattern, management style, power relationships and, most important, goals and objectives. That is the situation with UCP of Rhode Island, which is replicating many of the components of the model.

Among such components that affiliates might want to consider are

- How to develop an environment for the creation of consumer oriented action groups
- How data is gathered and disseminated to key service providers and consumer groups for action. This is not simply "dialing for information;" it involves community organization, political analysis, case advocacy and other strategies
- How to create a support network to help the advocacy coordinator and the project in dealing with opposing forces and interests
- How the affiliate's volunteer leaders are persuaded and enlisted to become more active in the advocacy effort
- How forums and arenas are created for consumer-provider discussions, which ultimately have an impact on decision making and planning for the developmentally disabled
- How the advocacy approach is integrated into the existing programs of the affiliate, changing and expanding them

- How specific programs are developed through working with community groups or with members of the affiliate's staff

Milwaukee

Milwaukee was selected as a project site in part because it is a highly industrialized midwestern city with a diverse population. It has many skilled professional agencies providing services to developmentally disabled children, but they did not appear to work in cooperation with each other. And no one agency appeared to take overall responsibility for continuing guidance to the families of disabled children.

The Milwaukee advocacy model was to include components of a case advocacy program offering individualized services, a consumer information program, legislative and governmental activities, fact finding and community organization processes. Among its projected outcomes were a neighborhood advocacy program in the largely black inner city, a legal advocacy program, improved comprehensive follow along services for high risk infants, and improved resources and services for the severely developmentally disabled. The latter included community residential facilities and increased recreational opportunities.

The project was discontinued after a year and a half. At the time of its inception, the Milwaukee affiliate had been newly reorganized, and it was expected to emerge stronger, quite capable of assuming a key role in providing and promoting services. The prediction proved inaccurate. Even though National UCPA attempted to strengthen the affiliate by placing national voluntary leadership on its board at National's expense, and also lending it funds, the affiliate was unable to strengthen sufficiently either its fund raising capability or its voluntary leadership. It is therefore difficult to determine the extent to which the weaknesses of the project can be attributed to the affiliate's organizational problems or to the model itself.

Achievements

There were, however, a number of positive achievements, and even the negative experiences provided some useful lessons that are already being applied in Kansas City, which was chosen as an early replication site to replace Milwaukee.

One of the major Milwaukee goals was "to improve the adequacy and appropriateness of both private and public services to the developmentally disabled." (See Appendix L.) An ombudsman was not only to investigate grievances, but to establish an information, referral and follow along program. This ombudsman service became perhaps the project's major activity, serving 106 persons in little over a year. It also became an effective service for consumers who had met with discrimination and for improving communications between consumers and providers of service.

Parents agreed that in this activity the advocacy coordinator had developed considerable personal clout, but—according to the site visit team—did not feel that this derived from the power of the UCP affiliate. The community as a whole did not perceive the advocacy project as part of an organizational program, nor the coordinator as a part of a network of people acting to bring about positive social change.

A second specific accomplishment of the project was the coordinator's initiative in developing legal services for disabled consumers. A grant was obtained for a legal advocacy program. Milwaukee Legal Services has been designated as the service provider, and the program is continuing.

Third, a newsletter, *The Developmental Disabilities Spokesman* (see Appendix M), proved highly useful to consumers, volunteers, providers and officials. It reported on the case advocacy program and community organization activities, monitored legislation and the implementation of laws, and provided the kind of information people need to be effective in legislative efforts. The *Spokesman* was described by one parent as "fantastic—it gave consumers useful information on the laws in language that was understood." The *Spokesman*'s analysis of public education laws was deemed particularly useful.

Fourth, fact finding projects were undertaken by University of Wisconsin-Milwaukee students under project staff supervision. The one study completed produced comprehensive follow up information on high risk infants who had been discharged from the Milwaukee County Hospital Neontal Intensive Care Unit, and led to the development of mechanisms for follow along of high risk infants during their early years of life.

Fifth, the involvement of an advocacy oriented coordinator with coalitions of consumer organizations and with agencies monitoring the existing service delivery system, resulted in improving services for severely multi-handicapped people, and greater concern for them in the planning process. Parents were grateful to the coordinator for identifying the specific barriers, practices and procedures which discriminated against the most severely disabled, and for the knowledge they gained about how to deal with the barriers.

They were also pleased that the project gave them an opportunity to meet other parents. The NAAC site visit team noted that most of the mothers taking leadership in the project were from white middle income families who had been living in Milwaukee only a short time. The coordinator sometimes called on parents as resources and support for other parents. They were proud of this role. One mother said: "Unlike professionals, we are living with our children and therefore have a certain understanding about our problems that professionals do not have."

Sixth, the Advocacy Advisory Council was developed into a forum with professional and consumer representatives from some 25 agencies. The process took some nine months, until the consumer parents understood enough about the intricacies and realities of service delivery systems to communicate effectively with the providers.

Some Unachieved Goals

In retrospect, it is clear that the momentum of the Milwaukee project was greatest during its first year of operation. When organizational problems began to pile up, the advocacy project and all aspects of the affiliate's work began to hurt.

Specifically, the site visit team noted four objectives which the project had been unable to achieve:

• The ineffectiveness of the advocacy council in support of all project activities, and its lack of visibility in the community. The feeling was that it had failed to live up to its potential or to achieve a proper leadership role. In part this stemmed from the fact that too much of the affiliate's regular business came to be conducted at Council sessions. For the newer consumers in particular, this meant too much time wasted on organizational matters, rather than on issues which concerned them.

Consumers were readily able to cite the action programs undertaken during the advocacy project—the high risk infants report, the legal advocacy program, the case advocate's activities, the publication of the *Spokesman*—but felt that a greater number of action programs with direct consumer involvement should have been organized by the advocacy council.

• The low level of case finding and community organization activities in the inner city. The advocacy council resisted making the inner city population a priority target of the project. The neighborhood advocacy proposal, for example, was never given the same stress as the legal advocacy program. As a result, according to one service provider, the project had almost no impact on inner city consumers or on the black community generally.

There was no real initiative to promote citizen participation from the inner city. Service provider agencies were contacted, but advocacy oriented agencies, such as the NAACP and the Urban League, were not involved, nor were the inner city media used. Aside from having few strategies for making the entire inner city community aware of the problems of its developmentally disabled, no attempt was made to show what inner city residents could do about such problems in a concrete way.

But was the seed sown? One inner city agency has now applied for a grant to accomplish many of the Advocacy Project's original objectives, and a health committee with representation from a number of inner city groups has as its goal a number of the UCP project's advocacy oriented objectives.

• Lack of effective coordination of agencies serving persons with developmental disabilities; and

• Failure to advance from case advocacy, as in the individual grievance procedures noted, to class advocacy and systems change, to make service providers more responsive to the needs of people with developmental disabilities.

Actually, attempts to achieve both of the above goals were made. At meetings with agency administrators, the advocacy coordinator often exerted his leadership as a spokesman for consumer interests. But, one professional commented, the coordinator might have been considerably more effective in the role of a catalyst; organizing consumers to represent themselves before these agencies. The same professional felt that the agencies with whom the coordinator met often gave lip service rather than actual cooperation. And they might have been more responsive to pressure by the kind of well-organized consumer groups associated with mental retardation organizations in the area. Had UCP's advocacy project mobilized such consumer groups, it might have made a real impact on service delivery systems in the city.

Some Conclusions

In summing up, the site visit team felt that those components of the project which had been successful were those which depended on individual activity: The case advocacy program, the *D.D. Spokesman*, the high risk follow up study, and the legal advocacy program. Less successful were the elements which involved community organization: The development of the advocacy council, the organization of consumer groups to support case and class advocacy, involvement of and impact on the inner city, and public education.

What would appear to be an underlying conclusion is that the success of an advocacy project—and, more important, the integration of the advocacy approach into the life of the affiliate and the community it serves—depends not so much on the individual efforts of the advocacy coordinator as on his talent for involving others. The creation of a network of people operating as advocates, alone and together.

Components for Replication

Kansas City's UCP affiliate was chosen to replicate the Milwaukee model because it was deemed to have the requisite organizational leadership, staff and financial strength to provide a truer test of the model's various components. Components other affiliates might want to consider include

- How an ombudsman program can function within an information referral and follow along service of a voluntary agency
- How to design and conduct action oriented research projects as a method of follow along among target groups with special needs
- How a newsletter can be developed for consumer education and to provide information about legislation, legal processes and governmental activities
- How grants and contracts can be developed to initiate such needed community services as legal advocacy and neighborhood advocacy

But in order to incorporate effective community organization strategies, replication of the Milwaukee model should also explore the following:

- How to develop consumer education and action quickly in order to promote consumer effectiveness
- How the advocacy advisory council can quickly become an issue oriented problem solving body, with short range achievable goals
- How the affiliate can develop a strong financial base and volunteer leadership

III. THE REPLICATION SITES

How To Replicate An Advocacy Model

The decision by the National Advocacy Advisory Council on selecting replication sites was invariably the result of a lengthy, complex, and thoughtful process. It might therefore be useful to describe some of the steps in that process as clues to the choice of Kansas City, Rhode Island and Illinois as replication sites and to indicate the help other affiliates might receive in considering their own advocacy projects.

For—let it be clear—the test is of processes and of components, and not of the advocacy approach. If the concept of advocacy itself is invalid, then so is the basic philosophy of UCPA and of every other organization working with and on behalf of disabled people. Given that, advocacy activities must still be tested and components assessed and evaluated to determine which work when, where, and in what environment.

The question which immediately occurs in a less-than-totally-successful demonstration is whether the model is faulty, or did other factors interfere? To find out, the problem solving method tries the model again, with negative factors and variables eliminated or controlled, at a second site.

The direct connection of National UCPA with the advocacy sites, and the source of help for advocacy minded affiliates outside the project, is the National UCPA staff, particularly Project Director Ernest Weinrich and Advocacy Coordinator Marie L. Moore. They have been a continuous source of information and guidance for participating affiliates since the National Advocacy Project began.

The dialogue started as soon as an affiliate expressed interest in replicating one of the advocacy models. Key people at the affiliate—board members, the executive director, staff—were asked what they expected of the advocacy project and to describe their own affiliate's activities.

In their turn, the project director and national advocacy coordinator described what had been learned at the model sites. Together, national and affiliate people then tried to determine what a local advocacy coordinator and council might be able to do to expand the accessibility of services for the consumer, increase consumer involvement especially at decision making levels in affiliate and community programs, how the advocacy approach might benefit the affiliate and its overall position in the community.

This initial dialogue usually took place at the affiliate. After the visit, summary reports were sent describing what had been learned about the roles of individual staff members of the affiliate, as well as clarifying the expected role of the future advocacy coordinator. This role was to be different from that of anyone else on staff. Yet the coordinator would need to work very closely with every other member. The difference was important. The coordinator was not to be just another pair of hands, nor even another brain, dealing with already ongoing activities or helping with business-as-usual.

This dialogue also helped to clarify that the role of the local or state advocacy advisory council would be not as an extension of the affiliate's board, but rather as an issues-action-results oriented body charged with charting directions and priorities for the advocacy project and helping to develop solutions once problems were identified.

After the affiliate had agreed to participate, the national staff people also assisted in screening candidates for advocacy coordinator. Naturally, the affiliate executive director made the final selection. Sometimes the choice reflected not only the candidate's talents, but his "fit" with the affiliate, its staff, the total environment, and the objectives of the model.

Once the advocacy coordinator had actually been hired, the national advocacy coordinator met with him or her to provide in-depth orientation about the National Advocacy Project, National UCPA and its relationship to the affiliate, and—perhaps most important—what had already been learned and was still being studied at other advocacy sites that might be applicable to this one.

One additional helpful step before actual replication begins is stressed by Dianne E. Smith, UCPA national program representative for the Southwest District—a visit by the affiliate's executive staff to one of the model sites. Ms. Smith cites such a visit by Mike King, executive director, UCP of Tarrant County (Texas), which is now contemplating its own advocacy replication, to UCP of San Mateo-Santa Clara.

For a small investment in time and money, she reports, Mr. King considered this "the most reasonably priced training seminar" he had ever attended. "Before the visit," she notes, "verbal explanation of the San Mateo-Santa Clara system had only established a 'thinking base' and was really not vivid or thorough enough . . ."

Although Texas and California laws and regulations differ considerably, Mr. King found that both the host affiliate and his own were oriented toward a system of indirect services, and that both shared a key assumption. In such a system, advocacy should have the major role.

"Person-to-person contact," Ms. Smith adds, "stimulated sequential thoughts and questions which would have been impossible via phone or letter . . . Of considerable usefulness was the discussion with each staff person as to how his personal service and program philosophy was satisfied through the advocacy-indirect service delivery system methodology."

Ms. Smith cautions, however, that the affiliate-to-affiliate visit will prove fruitful only if there is a sincere belief by both agencies that the advocacy approach to services is an appropriate avenue to pursue—and if the two agencies are, in fact, matchable in the most important organizational and philosophical respects. The national advocacy coordinator and other UCPA staff people can help affiliates judge whether such a kinship exists.

Greater Kansas City

Greater Kansas City (Missouri and Kansas) was selected as an early replication site by the National Advocacy Advisory Council because its location and characteristics were similar to those of Milwaukee. It is midwestern, industrial, with a largely unreached minority inner city population. As in Milwaukee, families in the Kansas City area had problems in getting into the service delivery system, and there was minimal coordination of services.

An additional reason for the NAAC's choice, according to Council's minutes of January 1975, was that "it was felt that the affiliate in Kansas City had the strength of able voluntary leadership and a

sound financial base. An advocacy program using the successful components of the Milwaukee model, plus appropriate community organization strategies learned from the other two models (New York and San Mateo-Santa Clara) would strengthen the advocacy stance of the agency, particularly in relation to the inner city . . ."

In answer to the questions of NAAC members, it was noted that "the affiliate's office is located near the inner city area, although no specific efforts have been made in developing needed services outside what is generally available . . . Recognizing the lack of outreach, the affiliate is restructuring its board and staff, consumers and parents are being added to the board, and there is a planned expansion for a broader financial base. The affiliate has already developed some portions of a legislative component."

Project Goals

Four goals were chosen for the Kansas City project, which started March 1, 1975. It is illuminating to see how, in a relatively short time, the affiliate has reached toward them. The goals are to 1) actively promote and support the participation of consumer groups concerned with the developmentally disabled in the determination and development of needed services, in order to enable the consumer to become an advocate for his own interests and participate effectively in decision making processes; 2) provide a channel for cooperative effort on the part of consumers, community representatives and provider agencies; 3) improve the adequacy and appropriateness of both public and private services to the developmentally disabled; and 4) initiate, influence and monitor legislation affecting the developmentally disabled.

The experience of all earlier projects, as well as common sense, indicates the essential first step in determining what needed to be done to achieve any of these goals was to get the facts, to take an analytical look at the systems involved: Service delivery, organizational, political, governmental. The latter was especially complex in the Kansas City project because it crossed state lines, involving both Missouri and Kansas. This is essentially "systems analysis". In less formal terms, it is: Who does what for whom? What and where are the missing pieces? Who can supply them? What will it take?

For example, en route to Goal I, it was first necessary to "analyze the developmental disabilities delivery system in the (K.C.) metropolitan area from the consumer point of view, with emphasis on service delivery gaps, overlapping, duplication, points of entry and flow." By the end of September such an analysis, complete with diagrams (see Appendix N) had been made. Also, based in part on the San Mateo experience, a brochure designed to guide consumers through the system had been drafted.

In June, the Local Advocacy Advisory Council undertook a problem census. One problem identified was that no adequate case finding mechanism existed. Sometimes the system turned out to be better than expected. Everyone was aware that there were no programs for high risk infants in Kansas City, Mo. Investigation found four and another on the way. On the Kansas side, one of two Wyandotte County studies under way to find people with developmental disabilities not being served also focused on high risk infants. Together, the surveys made it clear that existing treatment programs could not possibly meet the needs of all high risk infants in the area.

With regard to Goal IV, the LAAC and others were asked to help determine which legislative areas were giving developmentally disabled people the most problems. Among others, they focused on the Missouri Special Education Act, proposed day care licensing regulations in connection with Title XX funds, architectural barriers in federally financed buildings, and the interpretation of "gainful activity" in laws pertaining to sheltered workshops.

Consumer Involvement

One of the first steps taken to promote consumer participation was to set an example. Eight of the 19 original members of the LAAC are consumers and two other disabled adults were added later. When this happens, it advertises "Consumers Wanted."

Another indication was the manner in which consumer action came to supplement the ombudsman approach. An early instance was the failure to implement the Missouri Special Education Act. Seven grievances concerning inappropriate placements and failure to provide transportation were filed. In nearly all, ombudsman intervention was effective. "The case advocacy component of our project," notes Edwin B. Minter, executive director, UCP of Greater Kansas City, "is a very valuable notion in that the crisis need of an individual generally provides our council with another discovery of one of those 'gaps' . . . This component presents a myriad of service possibilities for a progressive local affiliate."

To deal with the gaps uncovered by the case advocacy approach—in both Kansas and Missouri special education laws, a coalition of parents and agencies, including the UCP Advocacy Project, convened a Right to Education Workshop for parents in August, to provide information and discuss strategies. A handout was distributed to parents (see Appendix O). As a result of the conference and its attendant publicity, parents have continued to call for more information. A series of follow up evening workshops is bringing parents and resource people together.

A great deal of information is also disseminated through the *UCPA Advocate* (see Appendix P) and compare with the *Milwaukee D.D. Spokesman* (Appendix M). There is also a legislative "hot line" to parents to help monitor programs and keep consumers informed.

Another demonstration of consumer involvement in getting laws implemented involved parents of children attending day care centers who were having difficulty with the transportation regulations. At one center at least one youngster was scheduled to be "left out" because the contractor-provider didn't have room for his wheelchair. With the tacit approval of the center's professional staff, a mini-workshop for parents, emphasizing tactics, was held. The tactics: phone calls, letters—new to this particular group. In two days the problem had been satisfactorily resolved.

"The times are ripe for consumerism by the handicapped," says Edwin Minter. "This point I make and share, purely philosophically. But really, it's 'our turn now.' Advocacy is a natural device to coordinate, support, lead and/or guide it!"

But sometimes philosophical or theoretical acceptance alone doesn't do it. As illustrations, when the Developmental Disabilities Council of Kansas City wanted to turn people out for a public protest, attendance was poor. One reason was that they had failed to ask consumers to turn out.

When Legal aid wanted to set up a legal advocacy program for handicapped people, they opened headquarters in the juvenile offices, an immediate put-down for disabled adults except that many never reached the point of finding this out because the building was replete with architectural barriers.

Learning from Milwaukee

One of the things learned from the Milwaukee experience is that too great an emphasis on the case advocacy approach can prevent the project from focusing on the more far reaching aspects of

advocacy. These are the aspects that will not only remedy individual grievances but impact on entire systems and change them. So that while the Kansas City advocacy coordinator responded whenever a consumer asked her to intervene with a school or service agency, there were only 10 such instances in the first six months of the project, compared with 106 in Milwaukee in a year. And it is understood that if the number increases substantially, the program is to be re-assessed.

Another difference is the determined effort of the Kansas City project to reach consumers in the largely black inner city. Most of the volunteers and leadership of the affiliate are white. The first step therefore was to recruit people from the black community as members of the Advocacy Advisory Council. They were then asked to help in assessing the attitudes of black consumers toward UCP and other agencies serving the developmentally disabled.

The first problem was how to find professionals and others in the community whose priorities match those of the advocacy project in working with developmentally disabled people. The second was how to get the advocacy project's message to people who had never been reached by UCP before and who might never want to join anything, but need to be reached.

The most incisive suggestion, which is already being followed, was to use the resources of the community itself. Churches, for instance. Since people who are not church goers often listen to church services on the radio, ministers will be asked to use information about developmental disabilities and the advocacy program in their broadcasts. In some areas, the YMCA is the only place youngsters can congregate. Informational materials left there hopefully will be taken home.

Clinics which serve children under six are located primarily in areas heavily populated by minority groups. People waiting have nothing to do but talk. Why not explore using the waiting rooms to reach people? But not merely to inform. These are people with needs. What do they need? Referral? Transportation? Child care assistance for mothers so they can attend meetings? Coming up with answers—and publicizing the resultant services. And finding new cases, reaching new consumers.

The impact? On the consumers, the "new" consumers, of course. And on the service delivery system. But also on the affiliate. In only a few months, the impact has already been noted. "The advocacy project," says Edwin Minter, "has contributed significantly to this agency's program in a number of ways.

"First, another process for determining gaps in the system is present, not only in the local affiliate but in the community it serves. This occurs because the advocacy project represents a viable modality in that community to deal with issues that occur as a result of identification. I emphasize this because it represents a neat and tidy approach to any affiliate that has traditionally been busily involved in a 'hands on' approach to service (and ours has).

"In other words, as a program service concept, advocacy can help a lot of people at one time in a 'hands off' way. This can be a problem in acceptance to boards of affiliates who have been measuring service success by counting therapy treatment versus dollars, and the old numbers game in general...

"I personally see (advocacy) as a considerable extension of local board service. Trained staff and other folks, with time, who are 'advocacy aware,' can often do the kind of things a board would not want to do. Advocacy presents another 'specialty' UCP needs."

Rhode Island

Once the Rhode Island UCP affiliate had been designated as the replication site for the San Mateo-Santa Clara model, another element of the replication process was brought to bear. The SM-SC coordinator visited Rhode Island to consult with their executive director, program director, and advocacy coordinator. Arranged by the national advocacy coordinator, this visit took place at the outset of the project.

According to a report on the visit, "areas covered included the processes developed by the San Mateo-Santa Clara project; assessing the environment; data collection and use; the role of the case advocate; building a network of supporters; agency changes which occur when a community organizer is hired; the arena for advocacy—found or constructed; and the development of specific programs." Differences in project site characteristics and their effect on the development of strategies were also discussed. An examination of Rhode Island's program component plan (see Appendix Q) shows how it is like, yet unlike, the San Mateo-Santa Clara approach.

The Rhode Island project began on July 1, 1975; within three months a State Advocacy Advisory Council had begun to function and UCP was already working intensively with consumer groups.

State Advocacy Advisory Council (SAAC)

The Advisory Council was so set up as to ensure broad geographical representation, including both agency and parent-consumer representatives. Of its 25-30 members, many were consumers and parents who had never before been involved in community activity; yet they plunged immediately and enthusiastically into the process of determining priorities for the advocacy project.

Contacts were established with selected service providers, consumer organizations and advocates. Internally, regular staff meetings were begun to involve the affiliate more actively in consumer issues.

That was an implementation of Executive Director James N. Fakourey's credo that "one of the primary missions of this project is to alert and educate the disabled adults and parents to the importance and the need of self-advocacy. I firmly believe that this will not minimize the role and influence of UCP and other voluntary agencies, but will increase our responsibilities as the clients and their families will be looking to us for professional direction and support."

Project RUSH . . .

There already existed in Rhode Island a means of identifying resources and needs, which the affiliate had been using as a basis for developing programs. This was Project RUSH, an acronym for Resources Utilization for the Severely Handicapped. It has now established a client registry, and provided consumers with a comprehensive *Rights and Resources Handbook for the Developmentally Disabled.* Compiled by a UCP task force, it covers laws, resources, and services and emphasizes the consumer's right to services.

Among the areas of need identified in the handbook are targets for today and tomorrow: Transportation, inaccessibility of public buildings, social programs for youths and adults, adult basic education programs, employment opportunities, more comprehensive special education regulations and the enforcement of existing ones, group homes for the nonretarded developmentally disabled, and

job skill development of the nonretarded cerebral palsied adult. Clearly this handbook figures large in the affiliate's plans for continuing information, referral and follow along services and programs.

and Project PUSH

Another acronymous group had been organized in the spring of 1975, a parents' group with the name coined in Heaven: PUSH—Parents Utilizing Services for the Handicapped. It is, for now, *the* UCP consumer group. It meets monthly to discuss problems of common concern, including advocacy issues. It is, however, only a beginning. The intent of the advocacy project is to expand consumer participation, especially of disabled adults, with the help of Project RUSH, which has already identified several hundred additional clients for the affiliate. This is a realizable objective, advocacy coordinator Teresa Smith feels: "Consumers are ready to become involved in being their own advocates."

How? At a meeting of PUSH the parents' discussion turned to the inadequacy of transportation for special education students. The first step was to find out what the state was supposed to be providing; the next, what changes needed to be made. Then the advocacy coordinator helped to focus the meeting on the methods and actions the parents could use to change the unsatisfactory situation.

The PUSH parents pushed and changes were made. Now that they know how it's done and have proven they're ready, perhaps next time there will be no need for the parents to push. To that extent, even the beginning of consumer involvement has already changed the system.

Executive Director Fakourey sees the project not only as "helping to educate the clients to their rights and the resources available to them," but as benefiting the affiliate itself. "This project is doing much to increase this agency's visibility and image in our community . . . (The Coordinator) has been doing an excellent job in strengthening our educational and recreational programs, and making many other agencies aware of UCP programs and resources," he says.

Comments Teresa Smith: "The advocacy coordinator has to get a lot of mileage out of his or her energies; and the only way to get a lot of mileage is to involve a lot of people."

Illinois

The State of Illinois was chosen as the replication site for the New York State model. No elaborate explanation is required to indicate the many similarities between the two states. This is borne out by the Illinois program component plan (see Appendix R).

Recalling the very considerable emphasis of the New York project on the legislative process and how the advocacy approach can affect it, it can readily be understood why the Illinois affiliate chose as its advocacy coordinator an attorney with considerble experience working with organizations serving disabled persons. He began his work in October 1975.

But in the view of Illinois Executive Director Jane E. Chapin, advocacy is much broader than the attorney's usual role—"exhortation or legislation/litigation or anything in between . . ."

To Ms. Chapin, advocacy "means any activity of a person or agency on behalf of another person or group of persons designed to protect or enlarge his rights and privileges." She feels that the advocacy project "will enlarge our advocacy role, give it a systematic basis, and make it more effective."

To her advocacy means not only "on behalf of". It also includes self-advocacy by disabled adults and parents to the "maximum extent possible. Incorporating this approach into our structure could strenghten UCP and hopefully other agencies."

IV. LESSONS — LARGE AND SMALL

Speaking of Impacts . . .

At this stage in the progress of the National Advocacy Project, it is clearly premature to draw definitive conclusions. Even in the case of Milwaukee, judgments are tentative and to be confirmed or not in Kansas City. There are more questions now than answers, but that helps. Questions are the first step to answers and conclusions.

Dr. Mildred Erickson raised one relating to the project's totality, when she asked "whether we really do have three different models of advocacy, or whether we really have three levels, three different areas, three territories in which our advocates function." In effect: "Is it the territory that is the difference? Is it the territory which makes the different models?"

Certainly there has to be a commonality of approach. Since this is life and not the laboratory, there need not be over concern about the purity of the model. While Kansas City is basically a replication of the Milwaukee model, it has borrowed elements and components from the New York and San Mateo-Santa Clara models.

How about goals and objectives? Management by objective? Monitoring the progress of the projects toward their stated goals has generally been found useful, but what if the actuality doesn't adhere to the model? What about unexpected outcomes, unintended consequences? Often, notes national advocacy coordinator Marie Moore, "the models evolved operationally according to the abilities of the people involved, including the local advocacy coordinator. His or her style, personality, desires and professional background did indeed help to make the program what it was." (and isn't that true to some extent of every professional?)

These are only a sample of the questions being asked. There are few answers yet. If conclusions are still far off, assessment of the impact of the project on the community, the affiliate and the consumer is even further away. At some point there will, of course, be final judgments and evaluations; for now, there are some interesting observations and comments.

Impact on the Community

No matter what the style, personality and ability of the advocacy coordinator or other staff person assigned the responsibility, the first step to be taken is what Dr. Erickson calls "assessing the territory"—the needs, resources, makeup of the population, the developmental disabilities system, and the gaps. To boil it down, as San Mateo-Santa Clara coordinator Bob Hansen did: "Where does the advocate go to do his advocating?"

His "context for advocacy," he concluded, was the entire developmental disabilities system in his territory. "Within and among these agencies and groups and the related planning and coordination

committees and official bodies, the coordinator sought to identify opportunities for additional parents of developmentally disabled children to advocate on their children's behalf." One idea that came to him was a sort of "small claims court" for consumers, especially from low income minority groups who do not know how to negotiate the system. But "unfortunately, there is not in the social service system, much less in the general public consciousness, a sufficient sense that such social, educational and health services as the developmentally disabled seek are entitlements—theirs by right—to make such a routinized claims court arrangement possible in the immediate future."

The point to be emphasized is that the impact desired is not on the developmental disabilities system alone, but on the larger "system," the community, the overall environment, the general public consciousness. Much of the impact of the Santa Clara Early Identification Project was not on the developmental disabilities system, but on a community which was not even aware of the existence of such a system. The tentative conclusion may therefore be drawn: The extent to which the community is affected or changed may well depend on the extent to which individuals and organizations outside the developmental disabilities system are recruited for the changing.

If the thought that the "system" can and should be changed is foreign to outsiders and people inside the system alike, what can be done to educate and sensitize them? To enlist those other populations? To communicate? Milwaukee's *D.D. Spokesman* and Kansas City's *UCPA Advocate* were not only informative; both helped to rally organizational and individual support for passing laws and implementing existing laws.

Not that everyone is equally eager to hear the gospel. Even within the system Bob Hansen found "people who like things the way they are, who have a stake in keeping things as is. They have a lifelong way of coping with people and don't want to bother learning a new way, even if it is more productive for the client."

Not just Santa Clara, California. And not just "people." Groups, bureaus, departments, organizations. Project Director Ernest Weinrich put it into a perspective based on more than one project's experience when he said: "The host agency will have to deal with barriers, with confrontations, even with certain kinds of outright hostility. For advocacy to work, the affiliate must start with a commitment to advocacy, and an understanding that such a commitment has certain consequences.

"If an organization chooses the advocacy route, it is because it wants to achieve its goals more quickly—to make the system more responsive to the needs of the people. It has to be a conscious decision, because anyone who seeks to affect change will also meet resistance. If there is to be conflict, it should not come upon the agency unexpectedly. The agency should be ready for it.

"Those of us who are involved in the advocacy project and are wont to call ourselves advocates, are interested in and have consciously undertaken two things: 1) To speed up the responsiveness of society and of any system in society to the needs of the people; and 2) to recognize that each of us is a change agent.

"Advocacy is not another program. All of our data collecting, all of our systems analysis, everything we do is related to change within our community, within our society, and even within our organization. Whenever we make a recommendation to help our organization, our affiliates, to become more effective in their activities, what we are suggesting is a way to change something.

"Whenever you bring change to an agency there is bound to be resistance; and when you say you're going to bring change, there will be even greater resistance."

Impact on the Affiliate

Another lesson extracted from the projects is that an affiliate engaged in changing the system and the community is itself changed. "When I talked with executives and board members at the sites which were considering replication of the advocacy project," says Marie Moore, "I told them we had learned from experience that advocacy means even the organization itself is not immune to being a target for change."

Depending on the affiliate, of course, the changing may begin with its acceptance of what National Advocacy Advisory Council Chairman Margaret Murray calls "a priority objective" of advocacy: "To increase consumer participation at all levels of the organization."

The beginning is setting an environment. "Both boards and staff members must share the philosphy that consumers are worthy contributors." By including "people with different life experiences" on boards and committees, affiliates "would gain new insights . . . and develop new energies to meet goals that have been planned together."

Mrs. Murray suggests that leadership training for board members might smooth the way to a more effective organization, and that consumer participation may "also require changes in how we do our work. Accessibility of the meetingplace, meeting evenings instead of afternoons, the necessity for interpreters . . . a commitment to include consumers must also include a commitment to see to it that they are able to attend meetings."

Leadership begins at the top. "The NAAC has discovered," Mrs. Murray notes, "that changes in their operating procedures have enhanced, rather than distracted from, proceedings and have created a more cohesive group that is cognizant of the needs of the total Council. It has created an atmosphere more conducive to accomplishment by forming a partnership with the disabled, as the IHF Plan proposed."

To reflect the commitment they have made to such a partnership, she adds, "some local and state affiliates have altered their bylaws to verify the inclusion of consumers at decision making levels." Not every affiliate will need to take the same step, but it is worth considering.

What happens when a local affiliate does pursue consumer involvement actively? John D. Halotek, Executive Director of UCPA of Greater Hartford (Connecticut), writes: "Working in concert with our Consumer Advocacy Council on legislation, architectural barriers, public opinion and in-house programming has strengthened the association's consumer and community credibility. This working relationship between consumer, staff and board of directors has reinforced the commitment of our affiliate to serving the needs of all developmentally disabled individuals residing in our geographic area. Our success with the CAC is a result of the proper melding of consumer, board and staff in identifying areas of concern and establishing objectives."

A measure of the impact of the advocacy approach on the agency is of course what happens afterward—new goals, new programs, a new look at the system, new faces at board and committee meetings, even a new way of looking at old situations and activities.

But, in fact, advocacy begins to have an impact the moment the affiliate decides to commit itself to that approach. "We do want to measure results," says Dr. Erickson, based on her long experience in community organization, "but one of the chief results is the process itself—how you engage and select consumers for training."

One measure of the advocacy projects' success is of course the extent of consumer input—in legislation and the implementation of laws in the New York State model, in changing the service delivery systems in San Mateo and Santa Clara Counties, and in participation of inner city minority consumers never before reached by UCP in both Kansas City and the two California counties.

The eventual impact can only be measured eventually; perhaps the total result can never be determined.

But, for now, a true and realistic evaluation of the projects should not rest only on what they accomplished. It may have more meaning to ask, *what did they begin?*

The Advocacy Approach To "Cases"

What were some of the specific experiences of the project advocacy coordinators in dealing with cases? And what conclusions can be drawn about what the advocate's role should be?

Because of individual abilities, skills, and backgrounds, the advocacy coordinators were to a greater or lesser extent drawn into case advocacy, or management, or brokerage. However, their feeling was that this often represented a diversion of their time and energies from their primary advocacy functions.

In Milwaukee, for example, the fact that the advocacy coordinator was involved in 106 case grievances is thought to have contributed to the lack of achievement in other areas. In emergencies, everyone pitches in, of course; but if the need is for a case worker or an ombudsman, get one for the job. Technically, the ombudsman deals with grievances inside his own organization. The case advocate deals with outside agencies. The same person can be both.

Where then is the advocacy function relevant to cases? What is the dividing-line? When there are enough grievances to show that they are not individual cases, then there is something wrong with the system as a whole.

For example, in Santa Clara UCP was confronted with the fact that the county Development Center for the Handicapped (DCH) was not serving some severely involved children with cerebral palsy. A direct approach was made to the DCH to insist on fair hearings, but as Cary Orr, UCP staffer with case advocacy responsibilities, saw it, the key development was what had taken place before. "Maybe our advocacy role came in listening to the consumer first, then setting out to change the system to make it provide the kinds of things the consumers had indicated they needed."

Virtually a textbook illustration of the process by which individual "soreheads" become "system changers" is provided by the history of PICS, the Santa Clara parents' group. In brief, when individual complaints appeared to be falling on deaf ears, PICS forced the institution of a fair hearing procedure, and lo and behold! a system had been changed.

There was not universal agreement about the advocacy coordinator's role with regard to cases. New York State Executive Director Bob Schonhorn saw the role of New York State Advocacy Coordinator Libby Wickes somewhat differently, because "nobody is now working with lower functioning people," and it is UCP's obligation to be their advocate.

In the New York model, one component provided for the coordinator to help train home service directors in using state laws and regulations, so they could assist consumers and parents in planning.

The coordinator was also to give the home service people technical assistance in dealing with cases—securing educational placements for children, maintaining services for people placed in institutions. Her actual assignment encompassed other tasks also.

Says Bob Schonhorn: "The core job of the advocacy coordinator is to teach people to be involved, to remain involved, to fight for their rights. At the same time, there are those who will never be able to fight for their own rights. What is the role of the advocate for severely disabled people? Is the coordinator going to teach them to be self-advocates, or is she going to have to spend the rest of her life advocating for them?

"There are certain people—much to my regret—whose lives we will have to control, more or less. For example, Libby is involved in setting up a home for children from Willowbrook. Is she an advocate in doing this? Yes, I think so. I think that that is a job for an advocate.

"Will the Willowbrook people become self-advocates? No. Will she be able to teach them to become self-advocates? No. Are their parents involved? Ninety percent of the time no.

"An advocate is not an advocate just for a certain group. If you're going to be an advocate, you're going to be an advocate. And there are different levels of disability for whom you're going to have to be an advocate."

The disagreement may be semantic. Advocacy, as we have seen, is given many interpretations. It may be who? In the end Bob Schonhorn agreed that case advocacy was in fact a proper task for case workers. But it may also revolve around one of the key questions the National Advocacy Project was and is determined to explore: How much *can* consumers do for themselves?

One facet of the question cropped up at the San Francisco workshop when Advocacy Coordinator Libby Wickes asked: "If you have to deal with the disabled person directly, and you want to try to work out an individual program plan, and if the person has never had any experience in being independent, how can he really participate in making his own plan?

National Advocacy Coordinator Marie Moore's answer was: "Even if the person says 'I've always been taken care of and I like it that way,' he is participating in his own plan. The case manager has to show him all the alternatives, and then let him choose." Added Project Director Ernest Weinrich: "The Joint Commission on Accreditation has insisted on client participation in the case process because especially in institutions even parents weren't being consulted or informed of their children's programs. In a voluntary agency, forcing the case manager to consult with the client means that he cannot just put a plan on paper. It means forcing him to help the client grow."

He may even grow enough—it would not be the first time—to become his own advocate.

The Case Manager As Advocate

Some additional comments from the San Francisco sessions may serve to illuminate how the site advocacy coordinators and others associated with the National Advocacy Project perceived the coordinator's involvement with case management and even with the closely related functions of program brokerage and program development.

Ernest Weinrich: The advocacy coordinator's role in case management is very limited or non existent. What he can do is to provide specific information or resources to help others be more

effective in case advocacy, if that is what they should be doing? (Note: the case advocate refers people to the appropriate agency, interprets their needs to the agency, gives the client or family information about procedures and entitlements, and if necessary accompanies them to get the service.) Actually, the advocacy coordinator operates as a case advocate only when there is no other case advocacy resource available in that community. Or else when he feels that that particular case can be used to change the service delivery system.

Teresa Smith: If the coordinator gets too bogged down in case advocacy, he becomes another case worker, not an advocacy coordinator.

Marie Moore: The coordinator also has to beware of the tendency of others to unload on him. In the first place, he can't do everything; and second, some of the things are inappropriate for him. His emphasis has to be on systems, not cases; on changing systems, not on settling grievances.

Weinrich: When you go in for changing systems, that's a scary business. The affiliate, and especially the local advocacy council, has to support the coordinator in helping him stick to his primary role, his real role.

Georgeann Chaffee: The advocacy coordinator might forego the case advocacy function altogether, except for the chance it gives him to see, touch and feel the real problem.

On Being A Program Broker

What happens if the case advocate or the agency for which he works tries to find help for a client or a family and finds that no provider wants to accept responsibility? Or that no relevant program exists?

He must then try to link two or more agencies so that they share the responsibility. In rarer instances, he may even press for the creation of new programs. This is no longer case advocacy, but a form of class advocacy involving improved case accountability, case integration, and program coordination. Many state affiliates are involved in such program brokerage through government administrative structures. In various situations, the staff person involved may be called a program broker, program facilitator, program coordinator, or even program developer. Whatever the title, and responsibilities, his job is to supply the missing link that will help keep people from being lost between the cracks of the system.

Some additional comments from San Francisco on advocacy and program brokerage:

Bob Hansen (San Mateo-Santa Clara): Before you can make any decisions you have to find out what's the problem, the grievance, the injury. Then, together with the consumer, see if you can specify the remedy. After that, you have to determine who makes the decision that would provide that remedy. The danger is that you can perceive yourself as just a program developer instead of a developer of advocacy by parents or clients. It is a hard job not to imagine you can develop a program yourself, but to get parents to think it through.

Weinrich: While the advocacy coordinator can on occasion help to put together resources and develop programs, the constant use of the coordinator that way would destroy his advocacy role and prevent community consumer groups from becoming self-directive.

Moore: Program brokerage and program development are not the same. Most affiliates have a program developer. But there are two different roles and functions involved. The advocacy

coordinator may have to be a program broker because for some reason a specific program cannot be developed. When the program developer runs into barriers in setting up programs, the broker has to find out what the barriers are and how they can be eliminated.

Hansen: The very human reason why the coordinator gets involved in program brokerage is not to seem to be just a "problem person," but also a "solution person." Get into program brokerage, and the affiliate will love you.

Smith: It may not be all that hard, once you get to know the system. It may be just a matter of bringing the people and the services together.

Weinrich: Or linking programs together so they work better for the individual.

On Using The System

In one way or another, in Dr. Mildred Erickson's summary, each of these functions was a procedure for dealing with the service delivery system. Specifically, "the advocate is a facilitator for bringing together groups. That's fine, but he must be aware of and use the existing coordinating mechanisms or organizations if they're there. Otherwise he will become a competitor of the planning groups . . .

"Do we need to look at the developmental disabilities council as a target group for our advocacy efforts and to make that a stronger group, since it does have the responsibility for overall planning and coordination of services? It then becomes a tool for a group for which we work, and the entity to whom we can refer problems that need to be looked at in a broader context—one that we can use in a different way, rather than trying to do its job for it . . .

"What we are really talking about is taking a look at what you have to work with, what are the agencies, the whole systems analysis of what is out there, what is the legal base, what is the function of those organizations and how hard they are exercising those functions or not exercising them, and who are the people in those agencies with whom you can work. Is the barrier truly a function of the agency's legal base, or is it an interpretation by the staff? Once you have identified the barrier, then you move toward your community organization function of finding out how to deal with it, at what level and with whom, and what you have to offer and what kind of support you can maintain . . .

"One of the elements of community organization is defining a problem, then taking a look at what group ought to be dealing with it, what group has the job of providing that service, and then working to get them on the right track. I think the easiest form of community organization, but not the best, is to set up a new agency every time you meet a new problem. You wind up spending so much money duplicating organizations and whole series or organizations that somehow are dealing with different little things. You then have a whole group of competitors for the territory, and you aren't getting the kind of service that people really need because those agencies have to spend a lot of their energy on survival . . .

"The community is not all that benign, and you have to recognize the competitive life of agencies. They are competing for survival; they are competing for clientele; they compete for money; they compete for status . . .

"If you decide to focus on what other agencies are not doing, it means that you have an awareness of what they are doing, and that you're not setting yourself up as an instant competitor, a usurper of territory . . ."

"The identification and utilization of community resources," commented Director of UCPA's Professional Services Program Department Ethel Underwood, "is a professional skill of a very high order." Added Dr. Erickson: "The advocacy coordinator's skill may be to say to an agency, 'Here's a need. We think your agency should encompass it, and we'd like to talk to you about it.'"

Another perspective is provided by the Kahn-Kamerman-McGowan baseline study on child advocacy: "Through bureaucratization and professionalization, the field may improve and upgrade its services, but it also runs the risk of becoming preoccupied with protecting its sphere of influence. Program consolidation may lead to better services for individuals, but it may also encourage fragmentation among programs. Thus, from time to time, and generally in the context of broad initiatives for social reform, an effort is made to shift the balance from consolidation to change, from perfecting an individual technique or agency process to improving or renewing systems."

There was agreement among those involved in the advocacy project that setting up a new program or facility is not necessarily the best way to change the service delivery system unless there is really no system. New York projected as a prime objective the creation of needed services and facilities in relatively isolated rural sections of the northern part of the state—an evaluation clinic and a preschool program.

Sometimes the needs of people with developmental disabilities cannot be met without a new facility or program. One may question whether this is an advocacy function. The advocacy minded affiliate will ask a simpler question: which staff person does it?

Exchanging Information

Exchanging information was one activity all advocacy coordinators found to be vital. They meant working out a system of communications with agencies and with individual staff members on matters of mutual interest and concern.

One of the more curious aspects of the system was that, while all project advocacy coordinators found immediately that they could not hope to function without a fund of data, frequently agencies dealing with developmentally disabled people were ignorant of what resources were already available in the community. It was not uncommon to find staff people who were unaware of their own agency's resources—the help to be found just down the hall.

When advocacy coordinator Bob Hansen was learning his San Mateo-Santa Clara territory, he found himself giving information just as frequently as getting it. Kansas City coordinator Georgeann Chaffee was exchanging information with a parent-agency coalition on laws and regulations, and there was a similar sharing in Milwaukee, Rhode Island and New York.

If information collection was a pragmatic necessity, it was also part of a process which had been anticipated by the National Advocacy Advisory Council as integral to the advocacy approach. In its statement on "Strengthening the Partnership between Consumers and UCPA," the NAAC had urged affiliates to offer their communities "communication with professionals working in service and consumer agencies, so that these professionals can become knowledgeable about available or needed services for the developmentally disabled and make appropriate referrals."

When Bob Hansen became an unofficial clearinghouse for information on San Mateo and Santa Clara County needs and resources, he himself became a resource for the community—an "authority" with statistics collected from readily available sources because no one else was collecting them.

Even in agencies which did not know what Hansen was doing, his data file opened doors for him and for the advocacy project. And on the other side of the door, sometimes in the unlikeliest places, he often found a kindred spirit, someone who eventually became part of the "support system" all agency professionals—especially advocacy coordinators—need.

Laws — The Advocate's Concern

Many voluntary agencies are committed to some forms of legal advocacy for the people they serve. That label may never be applied, however, especially if no lawyer is involved. In many situations, anyone who knows the law and who has enough determination can function as a legal advocate. This is aptly illustrated by a newspaper account (see Appendix S) of a Denver nursing home that sought to keep some people from moving out.

Primarily the story illustrates the support of the UCP affiliate for people who opt for independent living, at least more independent than the nursing home setting. When Denver's Dottie Christensen "immediately contacted the city attorney's office" to make sure "patients couldn't be held against their will" by nursing home employees, that was legal advocacy.

This form of advocacy, one of the oldest and most traditional, usually does call for a lawyer and usually does mean "going to court." For affiliates engaged in this form of advocacy, the National Center for Law and the Handicapped has identified a number of legal issues affecting disabled persons (see Appendix T). There are also a number of publications worth studying (see Appendix U).

But this approach was a component of only one of the models in the National Advocacy Project, the Milwaukee model, where the advocacy coordinator took the lead in obtaining legal services for consumers. A grant was obtained and Milwaukee Legal Services designated as the service provider, assigning an attorney specializing in the legal problems of the developmentally disabled.

Within two months there had been 20 referrals. However, the site visit team reported that half "have dealt with problems not directly associated with being disabled, while the other referrals have dealt with guardianship, institutional admission, and the right to edcuation."

Even if requests for legal aid had all been "associated with being disabled," hiring a lawyer runs counter to the basic thrust of the advocacy project. This is advocacy *for*, not advocacy *by*. Although for some people in some situations legal advocacy is an essential service, the UCPA advocacy project is about much more.

The San Mateo-Santa Clara Project deliberately decided to deemphasize legal advocacy. Coordinator Bob Hansen indicates why: "In the first place, it requires the retaining of legal counsel to advocate *for* the parent, whereas the project sought arenas where the parent as citizen had sufficient competence and opportunity to be an effective advocate for himself. In the second place, beyond the matter of expense . . . the citizen seeking remedy from a social agency through the courts must weigh the chances of winning in a reasonable time against an agency which has an interest in delay, and which is supplied with superior legal resources."

Under certain circumstances even groups of parents or affiliates sold on self-advocacy may feel compelled to retain a lawyer as a paid advocate. The commonest of such situations is where the entitlements of a group of disabled people are being denied. The advocate seeks, on behalf of a class, compliance with laws and regulations already on the books.

The traditional choice has been legal advocacy. Involving consumers creates another option. They may decide to go to court. But they may also decide they can get more out of going to City Hall.

"There Oughta Be A Law!"

What happens if there is no law on the books to implement? The obvious answer is to get the law passed. How recently has it been that there was no legislation covering people with developmental disabilities?

Legislative advocacy was a major component of the New York model, and consumers were involved at a number of levels, directly and indirectly. At the state level, consumer input consisted largely of proposals for legislation, as well as conveying their own sense of urgency and priorities. Though consumers did occasionally appear at legislative hearings, identifying needs and monitoring were handled chiefly by UCP staff and a legislative committee, which was reactivated as a result of the advocacy project. Previously the state executive director had been functioning as a one man legislative arm.

The advocacy coordinator played a considerable role in monitoring the state legislative scene. She provided local affiliates with facts, background on laws and their implementation, and such relevant information about the legislative process as how a bill becomes law and how to communicate in person, by mail, by telephone, with legislators.

Similar dissemination took place in Milwaukee, Kansas City and Rhode Island. In the Illinois replication of the New York model, the emphasis on legislative activity may be even greater. The state UCP office is located in Springfield, the state capital (New York City is 150 miles from Albany), and Illinois has chosen an attorney as advocacy coordinator.

The constant flow of such information to local affiliates and consumer groups throughout the state also helped to stimulate a reverse flow, New York State Executive Director Bob Schonhorn says. "Consumers have a great deal of input in our legislative package," he indicates. "Between 40 and 50 percent of the program comes from consumer recommendations. It was consumers, for example, who proposed two bills on transportation which have already been introduced. One involved transportation to jobs, the other to workshops and social and developmental programs. Consumers want the state to provide this kind of transportation. They don't want to rely on UCP affiliates or on their parents or friends."

In addition to pressures from year-round lobbyists, Albany legislators are often confronted by visiting delegations of consumers, unions and ethnic and other groups. New York State UCP once brought busloads of people, including some in wheelchairs, to Albany. But Bob Schonhorn thinks there is a better way.

"If disabled people want to fight, there's a better way to fight than to sit in wheelchairs in front of places. You write. You get your local legislator down to your meetings. You explain to him what you need. You explain what a viable organization you are, how many people you can influence, how many votes you can hold back. Every human being who is a voter is a potential threat to a legislator, or a potential ally."

To illustrate how local groups can bring pressure on legislators, he tells the story of a piece of discriminatory legislation which was brought to the attention of a UCP state conclave. As soon as they

got home, the delegates mobilized their affiliates, families and friends. Thousands of letters poured into Albany. The law was stopped.

It should be noted that local affiliates, volunteers, and consumer groups are urged to inform and educate their legislators also on their home grounds.

New York State Advocacy Coordinator Libby Wickes described some of the successes consumer groups in Suffolk County, Buffalo, New York City and Albany had in dealing with City Hall. She also noted that if consumers and parents are to be activated, "you need some sort of success immediately. Not merely to avoid frustration and quick discouragement, but to begin to recondition lifelong 'failures' . . . If you want to get them involved and keep them involved pick something simple. It's much easier to persuade legislators if not too much money is involved. Try something like access to voting booths or specific buildings."

Teresa K. Smith: Sometimes local systems are much more responsive than the state, especially in gaining levels of success for consumers.

Bob Hansen: On a long-range project, success may come sooner through the achievement of intermediate goals. Say the consumer group wants to make the whole city wheelchair accessible. A good place to start is the hospitals, but you quickly discover that it will take $175,000 just to make the major hospitals accessible. So you dicker about making at least a beginning with the hospitals' first or lower floors. If you can make it happen, two things have been accomplished in the way of progress: One, you've learned more than you knew before about the extent of the problem and the costs involved. Two, the consumers have a success under their belts.

A chapter on "How to Lobby and Get Results" appears in a rewarding primer, "How to Organize an Effective Parent Group and Move Bureaucracies," published by the Coordinating Council for Handicapped Children (407 South Dearborn, Chicago, Illinois 60605). It is full of such suggested actions for parents and consumer groups as a registration drive, march, rally, sit-in, boycott, teach-in, camp-in and public hearing.

Its advice on how to move a bureaucracy (or a state legislature or a city council): "You must stop feeling guilty and insignificant . . . you must stop apologizing . . . you must stop begging . . . you must not be patient . . . you must not accept those old excuses . . . you must stop whispering while everyone else is shouting." And such useful insights as "If a bureaucrat gives you what you are entitled to, he is your friend. If he doesn't, he is your enemy. It doesn't matter how friendly, how nice a bureaucrat is, if he does not give you the services your handicapped child is entitled to, he is not your friend."

Another helpful guide is the National Health Council's "Participation in the Development of Legislative Policy: Some guidelines for 501(c)(3) Tax Exempt organizations. It is available from NHC, 1740 Broadway, New York, New York 10016.

Why Systems Analysis?

It's fine to be prepared and to know how to confront a bureaucrat. But first you must know which bureaucrat to confront. Who is supposed to do what for whom?

In Kansas City, Coordinator Georgeann Chaffee's first necessity was to "analyze the developmental disabilities delivery system." In Rhode Island, Teresa Smith had to begin by "assessing the

environment." In San Mateo-Santa Clara the technical description of the model component is "systems analysis of services, programs and consumer groups, for developing community organization approaches," but Executive Director John Huckstadt has a simpler explanation: "Bob [Hansen] had to become at least as knowledgeable as we were about the rights and wrongs of the service delivery system before he could be any kind of vehicle for change."

Systems have been defined as complexes of elements in interaction (push here and something happens there). To know how the service delivery system can be made more responsive, it is essential, as one NAAC site visit team described it, to have an "awareness of established practices and how they interfere with making systems accessible to consumers in need, particularly . . . the unserved, underserved and misserved."

The advocacy coordinators of course had to become familiar with all the details of the formal bureaucratic structure, titles, names, and assigned responsibilities. But no sophisticated professional stops there. How the system is supposed to work is not as important as how it really works. What is the real community power structure? Who belongs to the establishment? What are the important policy issues? Bob Hansen found that in his area the latter were generally related to "sponsorship and funding—public vs. private, and state budget vs. local community budget."

It may take considerable perserverance to chart the system. When you know what an agency is supposed to do, you can at least attempt to make it accountable. But what if you can't find out? The PICS parents in California, Bob Hansen relates, found themselves caught up in the "agency game": "The active members share a frustration with their attempts to find out what the rules are for a given health, social or educational agency. Their experience with agencies . . .(which) emphasized the unique aspects of the family and brought out specific services, is . . . (that they) minimized or ignored the applicability of general policies and entitlements."

To make the service delivery system accessible to consumers and to help consumers themselves learn how to gain access, each advocacy coordinator had to map the territory, chart the system. To gain access it is necesary to find the right entries, not to waste time knocking at the wrong doors, or at doors that lead nowhere. As Bob Hansen says, "the shaping of program proposals is an implicit outcome of increasing familiarity with services and service gaps and barriers . . ."

The Advocacy Aspect of Data Collection

If systems analysis is essential to a productive advocacy approach, so is the collection of data and information. This is true of any program or function. In the advocacy approach, however, the collection process can be as important as the data itself. The means contributes as much as the ends.

It has already been demonstrated how the advocate may be able to develop an informal support system among professionals in other agencies, people who not only have information to give but are delighted that someone finally cared enough to ask.

But more important is the end-purpose of advocacy to involve consumers. The data collection process offers a means of involving them from the very beginning. "If a parent asks for data," says Bob Hansen, "turn it around. Tell him where he can get the data, whom to call, what kind of questions to ask. It is not that mysterious an art to get a little more data than the agency already has. Part of the genius of the advocacy approach is to turn that kind of request back on the consumer and to get him to learn how to do it." When that procedure was followed with regard to parents' grievances about

inadequate transportation for their youngsters, says Teresa Smith, Rhode Island coordinator, first the parents themselves were enlisted to find out what the actual situation was and what state laws and regulations called for; then "we identified what had to be provided. And in the discussion, the parents also came up with a number of their own suggestions for changes."

Facts are important. One consumer group was about to demand that the local welfare director follow procedures devised in the next state until they discovered that the procedures were illegal in their state.

Getting the consumer to get the facts is worth the effort, even if it takes longer or even if the advocacy coordinator could have done better himself. When the consumer learns how to collect information, he also learns how organizations work. If he is awed by professionals, he learns that the good ones don't want his awe, and the bad ones don't deserve it.

And what started out as data collection may sometimes become systems analysis—by consumers a little better educated, a little more sophisticated, a little bit readier to do it themselves.

The Advocate's Support Systems

The advocacy coordinator will not want to separate himself totally from data collecting. San Mateo-Santa Clara coordinator Bob Hansen's getting and giving of information was the key to his informal friendship network of provider agency staff members, consultants outside the developmental disabilities system, and consumers. This network he found so valuable that it was "nourished with periodic drop-in visits to their offices, telephone calls, and lunch or drink dates that offered more or less continuing consultation and cooperation in achieving goals."

Why so valuable?

"The advocate is out on the firing line. He is seen as somebody who is going to disturb the status quo—in a sense an unwelcome element," says Dr. Mildred Erickson, consultant to the SM-SC project. "One thing that concerned me a great deal was *where does the advocate get his help?*"

Because of its total environment, as well as its components, the SM-SC model offers a particularly rewarding insight into the importance of creating advocacy support systems. The need can in fact be anticipated: The advocate has to have such help available before he knows why, where, or when he needs it. As the NAAC site visit team stated, "Because the advocacy approach uses aggressive measures to bring about change, a backlash can be controlled by creating an informal network of supporting people whose basic philosophies are similar to the goals and objectives of the project."

On the firing line, "aggressive advocacy" sometimes translates as an "aggressive advocate." "The coordinator was a troubler of peaceful waters," notes Bob Hansen. "Health, welfare and education professionals, as well as the parents already influential in . . . developmental disabilities policy meetings, did not always welcome another advocate proposing that still other voices should be heard."

His foot-in-the-door was the UCP affiliate. He "built his initial relationships in the community on the reputation of his sponsors. He started with 'friends of UCP,' and over a period of time, such 'friends' made their own assessment of his abilities," and of the potential of the advocacy project.

Other Support Systems

The informal network was only one of the support systems Hansen came to depend on. He identifies three others—the Local Advocacy Advisory Council (LAAC); the PICS parents' group; and the UCP executive director and his staff.

"Until people get used to working with him," Dr. Erickson comments, "and until he has developed the trusting relationships with others, the advocate needs a home base" in his own organization. It is a natural base. "The executive director," says Hansen, with his staff, "represents the organizational advocacy of UCPA—a voluntary agency seeking services and opportunities for individuals with cerebral palsy and their families."

How crucial the support of the affiliate and its executive director are to the advocacy coordinator and the goals of the project was demonstrated a year after the project started in Santa Clara County, Hansen says, when the head of the major private agency providing services for the retarded undertook what "was clearly an effort to isolate the advocacy coordinator from his sponsoring organization. But the executive director had been kept informed of all the activities of the coordinator, had conferred with LAAC members as well as his core staff on the developing confrontation . . . and used the meeting to press a long-standing objective of the agency: To open the developmental disabilities planning process in the county to a wider range of consumers and providers, including UCP staff."

It was a showdown meeting, Executive Director John Huckstadt says. "It was a time for the agency to back off if it was going to back off. Or we could say: You're wrong, we're right, and we're going to continue exactly what we're doing, because we know we're doing it for the right reason.

"That's the message that we left with them that day. Maybe this was the first time I felt a sense of pride in our so-called adversary role because it was the first time I had been directly involved in it. Sure it was easy for me to sit behind this desk and tell Bob and others . . . to go out and fight the war again: OK, you can handle it, go back out there, go get them.

"But until I was on the firing line myself, and had that choice to make—maybe that was the turning point. It solidified my feelings about the project."

There was a wry epilogue, Hansen suggests. Because the executive director stood his ground, the UCP child services coordinator was later invited to join the committee writing the county developmental disabilities plan. "A 'nice' UCP professional could walk through the door opened by the 'bad' advocacy coordinator . . ."

The Funding Support System

"A staff that really believes in what it is doing" is one of the two essentials for a successful program, says Richard Miller, veteran UCP national program representative. The other is a "sound funding basis." To emphasize this, funds from the National Advocacy Project to model sites are being gradually phased out, so that affiliates will need to tap local and state sources to finance the continuation of the project. Other affiliates may contact the UCPA National Office for information on federal and other funding availability.

"An executive or a board may resist the advocacy approach," says Project Director Ernest Weinrich, "if they see it as a source of trouble . . . in a time of tight money . . .(which) will affect our

income. They are reluctant to engage in something which might reduce funds that support the entire program."

Bob Hansen notes that society's new awareness of consumerism "clearly and immediately affects the image of UCPA as a helping agency, as a seeker of voluntary funds, as contractor for public funds to provide public services, and as a partner to the disabled."

It would be foolish not to face the fact that there is a conflict between the traditional image UCP has portrayed through the media and the advocacy concept. Such services as therapy and medical care are thought to sell the agency better than consumer demands.

How the advocacy approach works, the new people it involves, and what it accomplishes, all become part of the answer to the fund raiser's question: What do I show the public?

The San Mateo—Santa Clara project proved that its advocacy stance could help in tapping another source of funds. Developmental disabilities assistance which were then being channeled almost exclusively to the mentally retarded, is now more available to all those with developmental disabilities. Such a shift was probably inevitable eventually; the advocacy approach made it happen sooner.

Of course there is no substitute for money.

If there were, it would have to be the San Mateo-Santa Clara volunteers who did what paid staff members would otherwise have had to do, the parents and consumers who contributed their time and their energies to advance programs and activities in their own interests and the interests of other parents and consumers.

Local Advocacy Advisory Council (LAAC)

Of all the support systems associated with the advocacy project, the one on which the coordinator found himself most dependent was his local advocacy advisory council. Officially, its support function was described as: "To provide consultation and guidance to the advocacy coordinator;" but as Dr. Mildred Erickson noted, "as a support system, the advisory council and its members can be used individually or collectively" in many ways.

First, its other assigned responsibilities are to assess and evaluate, as a continuous process, the effectiveness of the model and its components and to suggest more effective means for advocacy; to assist in collecting information and data on the needs of developmentally disabled people and the resources available; to assist the UCP staff, once the needs are identified, in solving such problems; and to assist the coordinator to interpret the advocacy program to the community, to other agencies and to government bodies.

Its most important service, however, is that by its existence it helps to create the climate for advocacy—what it is for and what it is. By bringing together volunteers, providers and consumers for a common purpose, says Marie Moore, the advocacy council "begins the advocacy process. Because for providers, association with consumers, even over a drink, breaks down the you-and-me.

"And it is deliberately designed to be responsive and flexible. It can give advice; it can set priorities . . it is supposed to be the consumer-provider body for dealing with both problems and solutions; it is the forum for action. It can do things that an official corporate body cannot.

"The councils came into existence as part of the advocacy project because the funding body insisted on a volunteer group to set policy. It was deliberately intended to be free standing, so there would be no conflict of interest with UCP's corporate structure. It is the base of operations for the advocacy approach; it does not interfere in the life of the host agency."

Bob Hansen: What this means is that the advocacy coordinator has been made responsible to the advisory council, not to the corporate body.

Ernest Weinrich: The advocacy council is supposed to give support to the coordinator in sticking to his real role.

Dr. Erickson: It must also be aware of what the climate is within which we are working and how the advocacy council relates to the total organization. It is not seen as something so separate that it has no access to the board. It should be able to use the board as its base when needed.

Teresa Smith: When I was asking people to serve on the council, I was asked about the possibility that the council would be in confict with the agency at some point. My answer was that we expect you may sometimes be in conflict, but that does not impinge on your right to do your own thing, to stand up for the right to do those things you feel you need to work on.

Georgeann Chaffee: I have found a multitide of specific uses for the council: To assist in the problem census, to find out where the real gaps in the system were, to compare the actual delivery of services with what's on paper.

Marie Moore: The council should continue to be as informal as possible, not only in what it does but in its own structure. It does not need a constitution or bylaws. These interfere with its work and the process by which it operates. All that is really needed is a copy of *Roberts' Rules of Order*, plus a planned agenda for the meeting. But it should have some feeling about itself and its purpose. Even when the federal grant for the Advocacy Project runs out, in this site or that site the advocacy council may have a life of its own, may want and be able to continue.

Dr. Erickson: The council must be wary of becoming too broadly active and losing its focus, because then it may find itself on a collision course with the agency. And this may affect its continuation after the grant runs out.

In San Mateo-Santa Clara, the LAAC met for the first time a month after the advocacy coordinator joined the affiliate. It included six persons—members of the UCP board, providers, and consumers. Subsequently the coordinator added people from the low income minority community and professionals from inside and outside the developmental disabilities system.

During its first year of existence, the LAAC was primarily concerned with helping the coordinator think through goals and methods, though it also specified priorities and formally adopted policies. It was, in the words of the coordinator, "predominantly an informal business which the minutes could not even summarize . . . All talked through their notions of advocacy, their views of personalities in major agencies, and their expectations, and tested their developing trust of one another."

Another of the council's support functions should be emphasized. As people of commitment and stature in the community, they served to reassure the UCP board and executive director about the coordinator's activities and about the progress of the project. To the community generally they witnessed, giving sanction to the project and strength to the coordinator.

On the State Level

While advocacy advisory councils were called for in all models, the one experience at the state level was less successful. There were a number of local councils and groups in existence in New York State when the advocacy project began. According to the NAAC site visit team, they had the potential to become a force in their communities if 1) members could identify achievable short-term objectives; 2) they had strong, enthusiastic leadership; 3) technical assistance, information and training were provided by UCP staff; 4) nonconsumer volunteers were recruited; and 5) they examined all program alternatives before deciding their priorities.

The New York State Advocacy Advisory Council (SAAC) was given responsibility for strengthening the local councils and organizing new ones; but the SAAC never really came to life. Instead state executive director Bob Schonhorn used his professional advisory committee and his advocacy coordinator to perform state council functions.

But the NAAC site visit team did find one consumer advocate who could see a useful role for a state council as a support system for local councils. "Having a state advocacy council behind the local people," said that advocate, "is a shot in the arm. Another resource behind the local group is important for testing your strength."

The Advocate's "Professional Style"

The original protocol for the National Advocacy Project lists a dozen qualifications to be used as guidelines in choosing the advocacy coordinator (see Appendix V). It adds that people having a number of the skills described could be drawn from the helping professions, the legal profession, the health profession and education.

One qualification is conspicuous by its absence. "It did not require a knowledge of cerebral palsy to be an advocacy coordinator," comments Marie Moore. "It was more important to know something about legal systems, community organization, group process, and working with people. Actually, the people chosen had differing skills, depending to a great degree on the orientation of the affiliate and its goals in the advocacy project."

When the Rhode Island affiliate decided to replicate the San Mateo-Santa Clara model, it chose for its staff what Ms. Moore calls "a professional twin" of the California coordinator. And the Illinois site, emphasizing legislative advocacy, chose an attorney.

"The models evolved operationally," adds Ms. Moore, "according to the abilities of the people involved. Yes, the style, personality and professional desires of the coordinator do indeed make the program what it is."

The criteria would operate even for a staff person taking the advocate's functions on as an additional assignment, though executive director James Fakourey of Rhode Island declares that "it has been my experience that the advocate must be a full-time individual in order to develop a comprehensive program and better serve the developmentally disabled."

"The advocacy coordinator," says New York's director Bob Schonhorn, "has to be a people person, somebody who deals with other human beings at the level they're on, who can accept the expertise of others and use it to the benefit of the disabled people they're working with."

Ernest Weinrich: A person who recognizes that things are in constant flux, and who is not too uncomfortable with constant change. A person who also has the ability to be a self-starter, able to function on his own. The first question one candidate asked me was, 'How often do I get supervised?' The advocacy coordinator should not be worried about who is going to supervise him.

Marie Moore: The ability to develop a relationship might be the first qualification. The second would be flexibility—not needing to have control, but to understand what's happening in the system.

Weinrich: Another characteristic is a pretty strong sense of ego and being comfortable with oneself.

Dr. Erickson: These are not really personal characteristics. The professional aspect is the conscious selection of the process you're going to use. The more understanding you have about people, and how feelings get in the way—how they can impede or enhance—then you as a professional will work better with a greater variety of people. Because you can move immediately to a peer relationship; you don't have to go through a period of one-up-manship. You should have a number of processes in your armamentarium.

It is not just being nice. It is a professional acceptance of people as they are, how they function, in the context of your job, your role. Anyone can learn it. Professional schools attempt to screen out those who cannot.

In the professions which involve dealing with people, we try to teach a skill—developing a relationship. We stress this in training, because without this ability you cannot do your job.

What this means professionally is that you're consciously able to tolerate differences, consciously able to help people deal with conflict constructively and realize this is a necessary part of the process. So that when you're setting up a committee, you consciously look for people with different points of view, even if they are emotionally involved. As a professional, your job is to help people make constructive use of this conflict, this tension, and to draw it off at appropriate intervals in appropriate ways, so they can move along and not disintegrate. Then you can help them find and see areas of agreement.

Moore: What sometimes works is the deliberately planned encounter. People should be aware that that is what it is, that it is to deal with issues, that it is to come to some agreement or compromise. In such an encounter you are saying I have respect for you but I don't agree with you; let's see if we can resolve our differences in a useful way.

The Advocate as Adversary

There are occasions when the advocate cannot avoid confrontation. "By the very way in which our system works," comments *Citizen Advocacy*, published by the President's Committee on Mental Retardation, "the interests of the client must be expected occasionally to be at variance with the interests of the agency. This places the professional in the middle . . . In some cases, the advocate must play the role of adversary to an agency . . ."

Moore: The program implementer is tied to some kind of agency structure, while the advocate is tied to the aggrieved person. And if the grievance happens to be against an agency program, the two may come into great conflict. The advocate may be hired by UCP, but he must make it clear that he is working not so much for UCP as for the consumers of UCP and other agencies. This is a distinction

which agency people or their agencies may not readily understand. A voluntary agency which allows itself to be co-opted by a government body—let's say the Mental Health Association by the Mental Health Department—stops being critical. In effect, it stops being an advocate. It begins to feel that it is part of the system, and must therefore cooperate with it. The real danger is that such cooperation will result unconsciously, insidiously, in less vigor on behalf of the consumer.

Bob Hansen: In the host agency, the work of the advocate and his commitment may compel him to be a burr under the case persons' saddle; but he should try to be a friendly burr. He must try not to alienate the other agency professionals. Sooner or later they will be working together.

Because "we can anticipate that people in the host agency will not always understand" the advocate's role, Dr. Erickson suggests discussions with them in advance of any conflict—"how you can anticipate areas of disagreement and what you do about them, what are the techniques." The key is the development of "good, sound, trusting working relationships," based on "open communication between staff persons and board members, and staff member and staff member"—what she calls "role clarity." This will help to sensitize the agency to what the advocate does and how it relates to the work of others. It is also "to let people know that the advocate does not desire to take over anybody else's powers, nor is he trying to build a power base for himself. Actually, the advocate's satisfaction is in helping other people to become self-advocates."

Almost the first item on the advocacy coordinator's agenda, National Project director Ernest Weinrich comments, is to sit down with the affiliate's executive director (and perhaps other staff people) to analyze the affiliate's structure and examine what the advocacy coordinator can contribute to the programs. This is of course good organizational procedures, but perhaps, above all other professionals, the advocate needs a secure home base. "The affiliate," says Marie Moore, "has to be a support system for the advocate, or his problems will multiply."

Affiliates, environments, staffs, problems, personalities, all vary greatly, but to Dr. Erickson, all of the advocacy coordinators have a common quality—a marked sensitivity in working with people to help them solve their own problems in dealing with the system. This, she feels, is the warp and woof of advocacy.

"I am struck, not by the big things that will change the world, but by the little things that will change systems."

The "Primary Process"

"Everybody seems to have an idea of what advocacy means and not necessarily the same idea," says Bob Hansen. "Is advocacy calling in lawyers to go to court? Promoting for new legislation? Speaking up for disabled children? Developing programs to fill service gaps? Going after more money? Being a more committed case worker than any other case worker?

"The advocate, whether consumer or professional, must be able to state the issue, stipulate the need . . . and specify what would be a satisfactory remedy . . . It is not complaining or pleading . . . In this conception, 'advocacy' means something more precise than 'speaking out for a cause' or 'fighting for a client' or 'trying to get things done.'

"The work of the advocate is not doing the jobs of case worker, or case advocate, or case manager. It is changing the system."

Dr. Erickson: One of the special skills the advocate has is to make a referral of a particular problem to the particular organization which has that job to do or, where no such service exists, to help create the service in his own organization . . . I am struck by the community organization aspect of what you do and how important this becomes . . . But you do try to use existing resources, so that you don't get into the position of trying to be the community organizer for the whole community . . .

In the San Francisco workshop discussions, it became clear that nearly everything the advocacy coordinator did was linked to community organization—"gathering and disseminating information," noted Bob Hansen, "and eliciting cooperative action among personnel of diverse organizations." And "legislative action," Ernest Weinrich added, "involves consumer action plus community organization." Also that "program brokerage is really community organization."

Dr. Erickson: Whether we are all using the same or similar processes, and no matter at what level it is happening, one of the things that is clear is the fact that the primary process is community organization . . .

Weinrich: The commitment of the affilate to advocacy . . . will have certain consequences. We use the traditional principles and processes of community organization in advocacy, because community organization can help the affiliate to deal with these consequences successfully.

V. INVOLVING CONSUMERS

Consumers At Decision Making Levels

A major reason why the Advocacy Advisory Councils help to create an environment for advocacy is that they bring consumers and providers together as equals. Advocacy casts consumers, perhaps for the first time, as something other than service receivers in the system. Ironically, consumers may be starting "at the top" because they have hitherto been barred from starting at the bottom as volunteers on other committees, working their way upward by normal organizational routes.

To show where UCP affiliates *used* to stand, at least, here are some findings of a 1971 survey on "The Status of the Adult with Cerebral Palsy as a Board, Committee or Staff Member in UCP Affiliates:"

Only 24 percent of the 227 affiliates that returned survey forms had one or more cerebral palsied adults on the board; 27 percent had an adult committee; 16 percent had one or more cerebral palsied adults as staff members . . .

To counteract these low percentages of consumer involvement, the report recommended that:

"Every UCP affiliate should re-evalute the role of the adult with cerebral palsy on boards or committees. Where no adults with cerebral palsy have been involved, every attempt should be made to find the individual or individuals within the community who could add to the deliberations of the board . . .

"In general, there is an obvious need for better understanding of the role that qualified cerebral palsied adults can play as committee and board members.

"The National Association, as well as every state association, should resolve to encourage all affiliates to expand the board to include adults with cerebral palsy, or to amend the bylaws to permit the adult cerebral palsied person to serve on the board . . .

". . . there is a lack of concern and interest on the part of most UCP affiliates in involving the adult with cerebral palsy as a 'consumer' in planning in the community. It becomes obvious greater efforts must be made in the recruitment of adults with cerebral palsy to become involved in affiliate activities."

Things are changing, however. The UCPA Consumer Activities Committee, at its second meeting in March, 1976, "were amazed to see a great deal of consumer contributions . . . in evidence, since many of the members are presidents and board members (of affiliates) and . . . have contributed many, many hours of service to UCPA."

To further consumer participation, the committee presented the following resolution to the Members of the Corporation of UCPA which was carried unanimously:

"WHEREAS, the National Organization has taken steps to foster greater participation by consumers at the policy-making level, including the establishment of the Consumer Activities

Committee and the installation of a policy of electing a consumer as a vice president and suggesting the inclusion of consumers on all standing committees, and

"WHEREAS, if consumer participation throughout the organization is to be meaningful, consumers must be involved in policy-making at the local as well as the national level,

"NOW, THEREFORE, BE IT RESOLVED that UCPA shall reaffirm its policy of urging state and local affiliates to include on their boards individuals with cerebral palsy, parents of children under 18 with cerebral palsy and other persons from the community without altering their policy of electing to their boards the best qualified people possible."

Advocacy Site Responses

Against the background of UCPA executive director Earl Cunerd's 1975 question—"Have we done enough?"—here are some recent responses from executives of affiliates participating in the advocacy project:

Bob Schonhorn: Consumer involvement? We tried; that was one of the things we wanted to do very much. After the 1971 survey especially, we tried to get consumers on boards . . . Out of 30 on our state board, seven are disabled adults . . . They range from 65 to a young man in his twenties who just got a master's degree in rehabilitation, and who has as much to say on the board as any other member . . .

"I would like to see disabled people play a more active part on state and local boards. But most important, I would like to see disabled people get together initially outside of UCP, and pressure UCP into making changes . . .

"Of 150 people on our state staff, five are disabled. We did not make a conscious attempt to recruit them. Nor do we make a conscious attempt to recruit blacks or Jews or Poles. I don't think there should be conscious recruitment . . . If a consumer is interested there's no problem being involved. We need new people, but I don't believe in soliciting . . . When we started the local advocacy groups, we ran across three bright young people who expressed interest in working at the state level. They were invited to a state board meeting. A year later they were invited to join the board. But people have to express interest. I can't force interest on them.

James N. Fakourey: Board of directors, one cerebral palsied adult, one parent; professional services program committee, one parent; advisory council, six disabled adults, eight parents; staff, one disabled person.

Jane Chapin: Board, 5 percent consumers; executive committee, 10 percent; staff, none at present . . . Board structure is largely out of our control, in hands of area affiliates. We have some influence on President's choice of members for the executive committee. We have not done a very good job with affirmative action in the area of hiring, although we are sensitive to it.

Edwin B. Minter: Our board currently numbers 23 persons. Four are consumers, two of whom chair key standing committees. Six are consumer representatives (parents). They were actively recruited and, in my judgment, we've just begun. But I add, with a word of caution, that recruitment in this area is more difficult than it appears. Relatively speaking, good consumers, like good staff and board members, are not all that easy to come by. But didn't someone say that about man in general!

National UCPA Gives Leadership

As for the national organization, in April 1975 there was no one with cerebral palsy on the Executive Committee. There were five disabled people among the 300 Members of the Corporation, and three of the nine standing and special committees had consumer representation—six disabled people out of a total of 100 committee members.

Rightly feeling that it was the national organization that should set the example, that same April the UCPA Annual Corporation Meeting noted that "the Executive Committee has recognized the importance of consumer representation and significant consumer involvement at decision making levels of UCPA, Inc.," and provided for a cerebral palsy consumer to be a national vice president, and for consumer membership on standing and other committees (see Appendix W).

The amended policy was a direct outgrowth of the National Advocacy Project. It had been vigorously championed by the National Advocacy Advisory Council. In the view of NAAC chairman Margaret Murray it represented "substantial gains" for the advocacy approach. "There was an educational process for UCP decision makers relative to the issue," she said. "The discussions promoted a higher level of grass roots awareness and involvement, and some impact was made in getting more representation from consumers on the board of directors and standing committees."

And, she added, "increased consumer participation in UCPA is both inevitable and desirable, and we need to address a method by which this change can be brought about most expeditiously."

In implementation of the newly amended National policy, the NAAC then recommended the monitoring of UCPA efforts at all levels to increase consumer sharing of key decision making positions, and whether this is in fact done "most expeditiously."

How To Involve Consumers

An advocacy council which puts disabled adults and parents on its roster and on an equal footing with providers and volunteers signals the community that consumers are welcome. But unless consumers are also added to the affiliate's board and integrated into the affiliate's other committees and activities, obviously the welcome is limited. The welcome mat has to be big enough for more than a token few to find room on. And the welcome must be real.

Some interesting points from the San Francisco workshop:

Teresa Smith: What happens when you bring parents and consumers into planning bodies and commitees whose members are professionals and providers? The consumers are usually very turned off by what goes on. Sometimes there seems to be a conscious, or maybe unconscious, effort on the part of professionals to exclude consumers. The professionals usually feel they're sufficiently equipped to represent their constituency. Among the ways of excluding are how people are seated, who dominates conversations, and the use of alphabet terms. These are really ways of excommunicating. I've gotten feedback from consumers who've attended meetings like that. They don't really want us here, they say. They're not really interested in what we have to say; they put us down whenever we say something. We really don't feel that we have a role to play here. The advocacy coordinator has to play a major supportive role in keeping parents and consumers *in*.

Bob Hansen: That's probably because 75 percent of the people attending joint consumer-provider meetings are providers. They come because they need to know other providers, and for other reasons

having nothing to do with the agenda. When they discuss providers' business, they use shorthand—not to exclude but because it's natural for them.

To maintain consumer interest we may have to set up, under whatever name, a consumer caucus to explain what is really going on and to reinforce one another. This doesn't have to be formal—it may be nothing more than a parking lot conversation between two people after the meeting adjourns, or a chat beforehand about the agenda for the meeting.

Georgeann Chaffee: If he's going to accomplish anything, the consumer must learn not to be too respectful of professionals and deliverers of service.

Ernest Weinrich: Consumers can play a very important role in the education of professionals and board members. We should not forget that UCP started because of parents with grievances. They were consumers, too.

Rolf Williams (UCPA national program representative): Board members think that a consumer who has jumped over the barrier of dependency can no longer speak as a consumer. The first job, therefore, is to educate the board. You have to make sure that board members are ready to let people with cerebral palsy become involved. If they have a communications problem, try to understand them. Some boards have actually fought against having consumers, or even parents, on the board.

Ethel Underwood: When I recommend a review committee, which meets prior to and after a consultation or survey visit, I'm adamant that it have consumer representation on it. When I look at a board structure, I raise questions about the involvement of consumers on the board. When an affiliate establishes a Professional Services Program Committee, it is explicit in the guidelines that consumers be involved. It is not always easy, but we try to stimulate the awareness of the affiliate to involve the consumer at every level of policy and decision making.

Dr. Erickson: Actually, the affiliate ought to welcome the questions the consumer raises about its operations.

Bob Hansen: Most agencies really believe they're getting consumer participation. The first step is to get them to unlearn what they think it is, and relearn what it really is.

Dr. Erickson: When you're working with consumers, you have to remember that they do have a point of view and that sometimes this makes agencies uncomfortable. The advocate recognizes this is part of the process of consumer involvement.

Teresa Smith: Our role as advocacy coordinators is to get away from paternalism. We should never get into the habit of doing things *for* people; we should do things *with* them. If you get started doing for, it's hard to change over to doing with . . .

"We should give people tools, methods, facts and an idea of the processes. We should say: "I won't do it for you, but this is how, and I will be here for support if you run into snags. If you aren't willing to help yourself, I can't be much help to you . . ."

Bob Hansen: The process isn't so much finding out what the problem is as encouraging parents and consumers to find out for themselves. You may fly in the face of conventional wisdom, but the more you show people by doing, the more they will *let* you do.

"Least Likely to be Consulted"

Among the answers to the 1971 survey on consumer participation were a surprising number which said in one way or another, "We don't have any consumers because we don't know how to get them."

To "get them" you first have to want them; but, as the Kansas City program description notes, "while the consumer is the individual most closely involved with services for the developmentally disabled, he is the one least likely to be consulted when changes are made in the service delivery system, or when program effectiveness is being evaluated."

The Hartford (Conn.) UCP affiliate has an active consumer run Consumer Advocacy Council. "My philosophy of consumer advocacy," writes executive director John D. Halotek, "is a sincere belief that an individual with cerebral palsy and his family . . . can best represent their constituency. The question of 'what makes you an authority?' is immediately dispelled when a consumer presents the argument that 'the proof of the pudding is in the eating.'

"If we ever expect society to honor the human rights of the handicapped, we must take the initiative in allowing the people we represent the right of designing their own destiny. The dictionary defines the word 'expert' as: 'one who is taught by practice.' In the case of cerebral palsy, there is a second definition—one who has cerebral palsy and acquires knowledge about it every moment of his life."

"Advocacy is a Necessity!"

Living with their problems, consumers are often motivated to activity because an acute need has arisen. Relatively few have the determination and the perspective to go on beyond that immediate problem. "A parent with an immediate service need for her child," comments Bob Hansen, "is not going to be interested in discussing process or legislation." (What happens to those parents who do enlist for the long haul? See the PICS case-history, page 126.)

If there do not appear to be any distinguishable characteristics for spotting consumers ready to become involved, determination clearly heads the special qualities needed for continued involvement and for leadership. Robert Williams is the former president of the Hartford (Conn.) Consumer Advocacy Council. Here are some excerpts from his own account of his "love affair with what now can be called 'the movement' . . .

"April of '69 found me asking my town, via a letter to the local paper, to sponsor a recreation program for the handicapped . . . it was my first act of advocating for the handicapped so it is close to my heart! In '70, UCP came into the picture. I got into the center as the youngest ever. The program director . . .was beautiful! She was the only person who listened to my ideas! It was she and the program director who made me my first 'mouth' (talking board); now I could communicate! I just went wild talking to everyone about a group that would be an advocate for our rights!

"It was called the Connecticut Association for the Physically Handicapped, and I was appointed to chair the bylaws committee . . . One summer's day, the CP center took a trip to Harkness, a state park set aside for the handicapped; well, it just happened that on that day the Governor was receiving the grand tour of the place . . . As he tried to take my hand to shake it, I shoved my board into his hand and started spelling as fast as I could! Of course, he didn't quite know what was coming down and praised me for learning my ABC's! My forehead and palms were bubbling with sweat; I had pins and needles everywhere . . . finally he caught on, and I said my thing, which was that the state was forgetting or writing off its handicapped!

"[Next was] getting UCP to set up a council of consumers. They must have seen the light because we have one! We got together and I was appointed chairperson . . .we like went wild. We tried to get into everything . . .

"How could I do all of this while in school? I wonder how I could afford not to be involved in it! Advocacy is a necessity! I have the ability to advocate for my people; who am I to turn away from a responsibility? I truly believe that! (As for) communicating with officials, we communicate fine once they've experienced my 'mouth'!"

It should be noted that even the most determined of self-advocates might not have succeeded in creating the Hartford Consumer Advocacy Council without the commitment of the UCP affiliate's staff. A fuller report on the work of the council by its current chairman, Beverly Jackson, will be found in Appendix X; but a letter from her makes it clear that even self-advocates cannot be labeled or categorized. To each his own motivations.

"I must admit that I am not a born advocate, as some people are," Ms. Jackson writes. "For this reason, I was hesitant about accepting the nomination for the CAC. But after much contemplation, I did accept. I felt that I had an obligation to try to convey not only my thoughts and feelings, but also the thoughts and feelings of my peers.

"Another factor I took into consideration, which to me personally is very important, is the feeling that the black handicapped should be seen and heard more. On the scale of importance within the council, this may not head the list. But when you think that the black handicapped is a minority within a minority, the importance becomes evident."

"A Minority Within A Minority"

In the San Mateo-Santa Clara County area, where Latino and Chicano communities comprise the largest ethnic minority, one goal of the Advocacy Project, Bob Hansen notes, was "increasing the participation of a more diverse group of parents . . . It has generally been observed that parents active in such roles tend to be white, of above average income, and in their 40's or older. The project, therefore, has sought to increase the participation of younger parents of lower and middle income and from ethnic minority groups."

There are agencies which, for special purposes, have found it beneficial to put consumers on the payroll. Dr. Erickson cited an agency which was dissatisfied with its service to the minority communities, but did not know how to break through staff resistance. The agency put minority people on its payroll. Staff then had to deal with them and learned a great deal from them. "It gave the minority group a certain amount of power in affecting programs, which it wouldn't have had in any other way," she reported.

For the agency or affiliate with no minority consumers on its board or committees, and which determines that their time too has come, some guidance may be in order. If an affiliate is seriously interested in reaching out to the Chicano community, for instance, says Dolores Garcia, the social worker-parent who is consultant to the San Mateo-Santa Clara Project, it is necessary to understand why so few Chicano mothers show up at meetings and conference. Not lack of interest; they have no one to leave the children with.

"Most of the time when we Chicanos get involved in organizations it is because of the one-to-one reaching out that has been done to us. That was how Bob Hansen got me involved in this project. One-

to-one, even if it is time consuming, is usually necessary with minority people. Such a person must be convinced that he is really wanted.

"It is going to take a lot of time before we have these people sitting at conferences, in decision making bodies, at policy levels. It will take a long time, but if you really want to do it, it can be done."

Having studied the earlier Milwaukee experience, Kansas City coordinator Georgeann Chaffee came to feel that the key to the reaching out process was first identifying the largely black inner city community's priorities. She did this chiefly with the help of minority members of her advocacy council. Then she set her goal at getting the message to people who have never been reached but who needed to be reached.

Going where parents are is sometimes easier than you think, suggests Bob Hansen. "Pay the five dollars" and join a school or center PTA or other existing parents' group.

"A Home To Come To"

Even parents with disabled children who know little or nothing about organizations have a need for each other. Doris Weber, a parent member of the NAAC, writes of striking up a conversation on a plane with a young attorney, whose year-old son had recently been diagnosed as cerebral palsied. "The young man's complaint," said the letter, "was that there was no support system for parents... Not one parent or person ever contacted them, and they certainly would have appreciated the contact . . . These are two intelligent parents, adjusting well . . . willing to work to help their child, and who may be open to participating in a one-to-one hookup to help another couple . . .

"It fortifies my belief that we've got to . . . establish better support systems for parents."

If such mutual support can be a boon to families when they first discover that their child is disabled, the need does not quickly disappear. Even for parents determined enough, committed enough, and involved enough to act not only as their own advocates, but to be advocates for others.

"You have the staff and the council to talk with when you come back from a bad meeting bloody and bruised," said one of the Santa Clara PICS parents to the advocacy coordinator. "The activist parent needs a home to come to, too, when he gets into advocacy."

PICS -- A Case In Point

A child of the San Mateo-Santa Clara project and now living a lusty life on its own is Parents for Improved Community Services: PICS. Its history may furnish some insights into what may be expected of the consumer groups whose creation is an objective of the advocacy project.

The chairman of the Advocacy Advisory Council, which brought providers and consumers together, was himself the father of a severely involved cerebral palsied youngster. He consistently favored a more militant advocacy approach, and in the spring of 1974 became convinced of the need for a separate more activist group. This was to be a parents-only group; although PICS leaders continue to be members of the Advocacy Council and help set policy for the advocacy project, when they function as PICS they feel they are not constrained by any organizational policies or procedures but their own. Of course it works both ways—PICS actions do not reflect necessarily on the project or on UCP.

Shortly after the founding of PICS, two children (one of them the chairman's) were excluded from the services of the Santa Clara Developmental Center for the Handicapped (DCH). This triggered PICS' first campaign. It succeeded in having a fair hearing board appointed and the exclusions reversed. One service provider commented that "a very significant change has come about in parents who have gained confidence and strength through the establishment of this fair hearing procedure. If this project had not been available, they would have become additional 'embittered parents.' "

With this confidence and strength, PICS then went beyond the relatively narrow advocacy arena it had constructed and next focused on the regional agency which provides diagnosis, counseling and purchase-of-services for developmentally disabled people in Santa Clara County. It asked that agency to set up similar appeal procedures, and proposed a number of other changes based on consumers' experiences (see Appendix Y).

Not only has PICS attempted to get such appeals procedures adopted as a statewide model, but their existence itself may be a model. Already parents from San Mateo County have attended their meetings and have asked the advocacy coordinator for help in forming a PICS-type organization in their county too. Perhaps even more interesting is the ripple effect which has begun among parent organizations in Santa Clara County that have not been associated with PICS and that do not altogether accept the PICS approach but like the PICS results.

Meeting in private homes, some eight to 15 PICS parents do their own systems analysis (see Appendix Z), reach their own conclusions and decisions, discuss strategy, and then communicate with agency administrators and executives. The advocacy coordinator and other providers are occasionally invited to meetings as resource persons, but PICS is determinedly for parents only. To some extent this is for the protection of the professionals, who thus do not have to be involved in interagency confrontations.

But chiefly it is for PIC's sake. On one occasion a provider guest did ask to join, but PICS had already concluded that his agency was a target for advocacy and turned him down. As the PICS co-chairman (who was also the advocacy council chairman) stated to the group and the applicant, "We know how convincing an agency administrator can be when he tells a consumer why the agency can't meet his request. Here at PICS we simply don't want to risk being persuaded that what we want changed is impossible to change. We therefore prefer formal written communications, with written policy statements in reply, which can be reviewed and possibly reversed. (The advocacy coordinator—a sort of midwife to the group—notes wryly that even he may be excluded at some point.)

Many service providers understand and even endorse this point of view. "Our primary orientation to the parent," one notes, "is in relation to his expectation of our agency, and our agency's expectation that we will deliver service in a way that keeps that parent happy. In contrast . . . the advocacy individual perceives the parent consumer as an individual with potential to effect a change in the service delivery system . . . I think it impossible for professionals engaged in service delivery to develop this consumer potential, even if time were available from service delivery efforts."

PICS acknowledges its substantial debt to the advocacy coordinator. Chairman David Perloff cites his many contributions—his helpfulness, for example, in identifying agencies and individuals providing specific services, in furnishing clerical backup, and perhaps most of all, in helping the group learn how the system works and how it can be changed. A PICS founder sums up the relationship by describing the group as having become self-sufficient in pursuing its goals, but still needing to rely on the advice and professional expertise of the coordinator, particularly on using political processes effectively. Prior to PICS parents really did not know what impact they could have on the system. They have now found out.

PICS children have a variety of disabilities—retardation, orthopedic handicaps, autism, unusual neurological problems. Despite differing needs, PICS' activist stance has apparently been responsible for maintaining the parents' continued interest and support.

PICS' approach is to encourage every concerned family to advocate for its child. PICS does not attempt to judge the validity of the claims. But as a group, PICS is more interested in systems change than in individual grievances. Agencies frequently prefer to dwell on the unique aspects of a case, and minimize or ignore the applicability of general policies and entitlements. PICS counsels parents to de-emphasize the singularity of their problem, to focus on categories and issues instead, and to try to find out what the agency's rules are. If it turns out that the agency isn't living up to its own rules, the problem is to compel it to comply. But what if it turns out that the rules are there, but they are faulty and need changing? That, after all, is how PICS got started.

Looking at agencies and disabilities services as component parts of a system provides the tie that binds PICS parents closely together.

This sort of togetherness—plus, of course, PICS' reputation and its "track record"—may explain its continuing vigor and vitality. It is a model which might be useful to other parents' groups plagued by the usual high membership turnover and dropouts.

The parents who founded PICS were particularly qualified for their task by virtue of background, experience, skills and temperament. PICS is a tribute to them that in no way diminishes the contribution of the advocacy project.

Or of the advocacy approach.

How Do You Get Consumers "Ready"?

Even though the experiences of the National Advocacy Project are still limited, nonparticipating UCP affiliates are already beginning to look to it for answers. Advocacy is on a great many agendas these days.

One of the problems and concerns faced by UCP of Iowa, in its efforts to organize consumer coalition or advocacy groups, is that "partly because they have become accustomed to a dependency role, we find that very few of our consumers are psychologically ready to make the jump from consumerism to advocacy."

National Advocacy coordinator Marie Moore's answer is worth quoting: "Making the jump from consumer to consumer activist is difficult for most of us, and particularly for those who have experienced only a role of dependency. It has been my observation . . . that some were able to make the jump if they were already passively involved . . . Other people require a lot of individual or group support, while it is unlikely that some will ever make the jump. It has been my observation that small groups of people need a specific issue around which to organize (such as architectural barriers) in which they can have a plan of action for change (such as ramp curbs) . . . Once the small group has tasted success, they can handle more than one issue at a time . . ."

Groups begin to develop as change agents, she adds, when "something is not arranged for them but by them . . . Many consumer groups within an affiliate have begun to mature when staff or volunteers stop making arrangements for the group, but offer support services so they can make their own arrangements . . ."

New York State executive director Bob Schonhorn agrees that not enough consumers are getting involved, even when they have opportunities to do so. Most have never had participatory experiences. They have no real confidence in their ability to achieve results, to produce changes, to force systems to respond to their needs. Disabled adults especially, traditionally shut off from learning-by-doing, need to be trained. "Our experience has been that even after you set consumers in motion they're likely to fall flat on their faces if you walk away without training them. We started consumer groups with the prior assumption that they had within themselves the capability for leadership. This was wrong. The moment the support of the advocacy coordinator was taken away, the groups started going down to nothing. Groups must be trained to exist."

Not just groups, he feels. The advocate must aid individuals to get ready too, even though it means working himself out of a job. "That's the whole purpose of training. We may never do away with advocacy for others, but people should be taught to do self-advocacy."

To train consumers, the New York advocacy coordinator works directly with local groups, spending a day or so at a time with each, working through problems, analyses, tactics. She also helps train home service directors to work with local consumer advocacy groups in a continuing role.

The Advocacy Project developed some other ideas about getting consumers ready. Marie Moore says, "In the words of one of our advocacy coordinators, the best training comes to a group when they can clearly identify what an injury is, clearly identify the remedy in solving the problem, and clearly determine what their action must be.

"I would therefore recommend a workshop type of format, in which your key leaders can gain skills for problem identification and problem solving."

Such a workshop should be less concerned with theories of advocacy than with the specific concerns of the consumers in the room—the probable arena, for instance, and the system they will be dealing with. The experience of the San Mateo-Santa Clara project, to cite an example, was that parents who had been through the mill tended to focus on state and private agency services, while "new" consumers were more interested in schools, county health agencies, community recreation departments and such local services. Each group may have a different requirement of the training sessions.

Various aspects of readiness training can be handled by staff people, by board members and volunteers, by more experienced consumers, by willing consultants. In the Milwaukee project, the attorney hired to be legal advocate also offered to train volunteer advocates.

Whether the training is one-to-one, group sessions or more formal workshops and seminars, care must be taken to gear the materials to audience levels and interests. In the California program, workshop material was presented to a Spanish speaking consumer group in Spanish. In Kansas City, when parents of youngsters in day care centers needed help in dealing with inadequate transportation, a tactics training session was held. This is the kind of "specific issue" cited by Marie Moore. The focus was on action, and the parents immediately applied the tactics they had learned, with the result that they got the remedy they had been after in two days.

But tactics are not enough. In the long run, consumers need to learn how systems work, who else is slicing up the money pie, who has the power to make changes. Charts and diagrams of local service delivery systems can be useful. General printed and audio-visual materials, as well as technical assistance, are available from UCPA.

In the coming months, various processes for training consumers—especially disabled adults and members of minority groups—are to be tested at the project sites. One aid strongly recommended by the National Advocacy Advisory Council as a form of continuing education is "a consumer information service, using newsletters of UCPA and other provider agencies and consumer groups." Each of the project sites has provided such a service in its own way.

New York also stressed newspaper publicity, in line with the NAAC recommendation "to inform the general public of services available, and use other public education methods."

What is involved in getting consumers and consumer groups "ready," as Dr. Erickson sees it, is that individually and collectively they have to learn not only facts, but a whole process. To most it is the uncharted territory of "how to look at a problem, how to define issues, how to select options for action—and then move into action."

The phrases "parent power" and "disabled power" are now beginning to come into vogue. If they are to be something more than catch words, then consumers—parents and disabled people—have to learn not just what they are, but how to use them.

Especially parents who may have been bullied into submissiveness by bureaucrats and agencies in the "system." Especially disabled adults who have been conditioned all their lives to helplessness.

Those committed to the advocacy approach may need to be patient. The unconditioning process may take time.

VI. ADVOCACY AND UCPA

How To Begin: Some Guidelines

As the National Advocacy Project continues and as more and more affiliates adopt the advocacy approach to meet the needs of people with developmental disabilities, new lessons are certain to generate. Already the experiences of existing sites provide some valuable guidelines.

These are not to be taken as hard and fast criteria for success, but as what has or has not worked for others. Among the areas which the project has examined and clarified are: criteria of an affiliate's readiness; creation of an Advocacy Advisory Council and its responsibilities; responsibilities of the advocacy coordinator; some of the qualifications for that job; and a number of the mileposts which the advocacy program ought to pass during its first three months of operation.

Criteria Of Readiness

The affiliate is ready to begin when

- It recognizes the need to change the service delivery systems so as to make them more responsive to the needs of consumers and is prepared to press for such changes without fear of conflicts which may be entailed
- It accepts the fact that certain changes may also come about within the affiliate itself and affect its own programs
- It accepts the advocacy approach as the single most effective and expeditious method for bringing about the necessary indicated changes
- It has a good reputation in its community, strong leadership and a sound financial base
- There is support for the advocacy approach from its key leadership—board president, chairman of the PSPC, executive director—and from other staff members

Advocacy Advisory Council

After the affiliate has reached its decision, the first concrete step may be the selection of the advocacy coordinator, or the creation of the Advocacy Advisory Council. In any case, the council preferably should not be formally attached to the corporate structure of the organization. This allows it to pursue its advocacy role with no conflict of interest. It does not need to weigh organizational programs, policies or commitments against the rights and needs of people with cerebral palsy and other developmental disabilities; its concern is *always* the consumer, the disabled adult or child, the

family. Sometimes, in fact, advocacy of consumer interests can mean that the host agency itself becomes the target for advocacy, and its programs benefit as a result.

The membership of the council should reflect the ethnic composition and income levels of the affiliate's geographic area. Optimally, at least 25 percent should be adults with developmental disabilities and another 25 percent parents. The affiliate's board and PSPC should be represented, as should other local voluntary agencies and service providers (by professionals from a variety of disciplines). It is also helpful to have an attorney and a legislator as members.

But, above and beyond group and professional affiliation, council members should share a concern for positive change, a willingness to deal with controversial issues, and a recognition of the multicultural character of modern society.

The Advocacy Advisory Council must accept as its responsibility

- To establish the priorities for advocacy's programs goals and objectives
- To provide guidance and support for the advocacy coordinator
- To evaluate the program continuously in order to determine its most effective areas, processes, and components—and improve or change them when necessary
- To provide a forum for consumers, service providers and community representatives where problems can be identified and specific solutions developed
- To develop, disseminate, and promote program proposals

Local councils should relate to their state council, and of course to the National Advocacy Advisory Council (NAAC).

Advocacy Coordinator

It is worth juxtaposing the responsibilities of the advocacy coordinator with those of the council, to see how the coordinator's efforts implement and supplement those of the council. Among the coordinator's responsibilities are

- To organize (when necessary) and work with the council
- To develop consumer actions to secure needed services from the appropriate government and public agencies
- To collect data in support of needed service related legislation
- To help consumers and private agencies achieve greater influence in the planning and decision making processes of service delivery systems
- To work with representative community groups to guarantee that minority and disadvantaged consumers obtain required services

- To compare the utilization of services by families with developmentally disabled children from high and low income groups, and from various ethnic and minority groups

- To organize groups of parents and disabled adults for educational and social action purposes

One practical lesson has emerged from the National Advocacy Project. No program is likely to succeed unless it becomes the advocacy coordinator's major, and preferably sole, responsibility.

Whether the coordinator is someone already on the affiliate staff or newly hired, his or her qualifications should include

- Knowledge and skill in community organization and planning

- Specific experience in assisting consumer groups to identify service needs and to undertake actions to meet those needs

- The ability to work effectively with disabled persons, with parents, service providers and community representatives, including those from various minority groups and income levels

- The ability to analyze data in order to identify specific areas and systems where changes are needed

- Personal courage and the determination it takes to become a change agent

Getting Under Way: The First Three Months

Each advocacy program will develop in its own way, based on the special strengths and needs of the affiliate, its consumer population, local systems, and circumstances. The affiliate may not adhere precisely to the suggested timetable, but it should adopt schedules, milepost objectives, and a work program for the advocacy coordinator.

The coordinator's first month on the job will focus basically on orientation. Among the matters with which he or she must become familiar are the National Advocacy Project materials, unsolved client problems previously identified, the extent of the agency's involvement in governmental activities, the agency's community organization functions, its plans for continuing information, referral and follow along services for specific targeted populations, its program development activities, and the involvement of existing volunteer committees and consumer groups in agency programs.

Depending on the specific area or activity, the coordinator's major resource persons will be the affiliate's executive director or program director. Help may also come from the chairmen of the professional service program and legislative committees and from agency officers and board members.

By the second month, the coordinator should be well launched into organizational activities, including

- The establishment of an Advocacy Advisory Council

- The development of goals and objectives and plans to achieve them

- The formulation of a plan and schedule for each program component

- Community organization efforts with both individuals and agencies focusing on selected target populations and unserved consumers

By the third month, the advocacy coordinator should have been able to develop specific strategies for implementing the plans and have begun that implementation. He or she should also be able to prepare a progress report for the Advocacy Advisory Council and UCP staff.

Some Other Resources

These guidelines should be treated only as a point of departure. Local circumstances and conditions will dictate specific adaptations, emphases, and priorities.

In working out these adaptations and priorities, the affiliate may well wish to consult with those UCPA staff members who have been most deeply involved with the National Advocacy Project, including the director of the Professional Services Program Department, the project director and the National Advocacy Coordinator; or with the UCPA district program representative. A useful UCPA resource list is also available.

To sum up the basic lesson of the project, advocacy doesn't just happen. The advocacy approach doesn't generate spontaneously. Advocates are more often made than born.

Processes and acquired skills are involved. Between thinking about advocacy, and doing advocacy, there is a great deal to be learned.

"Inevitable and Desirable"

One of the most important consequences of advocacy is change. "The only way UCP will continue to be effective," Bob Schonhorn of New York State feels, "is to remain dynamic. The only way you remain dynamic is to have people look at you and say: I went through this and it's no good, and you have to change it—and bring all sorts of pressure to bear. It's very difficult for an affiliate to live with this; and yet it's the only way an organization like ours can live."

But the advocacy approach is only one of a number of routes which UCPA and its affiliates can take. True, it would appear from the advocacy project experiences that it is one of the quickest methods by which a voluntary agency can help meet the unmet needs of those it is serving. And quite clearly it is a most effective means of making service delivery systems more responsive to the needs of people with developmental disabilities.

In changing the service delivery system, UCP will also be changing, sometimes in ways which cannot entirely be predicted or controlled. Help parents and disabled adults to become advocates, get them involved in bettering programs and services, and they may one day tell you that your own programs need bettering.

"True," says Bob Schonhorn, "there is resistance to consumer involvement; but it cannot continue."

It is a view both confirmed and augmented by National Advocacy Advisory Council chairman Margaret Murray: "Increased consumer participation in UCPA," she declares, "is both inevitable and desirable."

Why inevitable? Says Mrs. Murray: "The concept that individuals with disabilities are entitled to full legal and human rights, and to full participation as citizens, gathers momentum daily. It is vitally important to understand that the Federal Government, as well as private agencies, support this concept." Spelling this out, the book *Citizen Advocacy* declares that "human services are increasingly being interpreted as rights rather than privileges, and such service consumers no longer cringe passively before the formerly god-like powers and/or posture of the agency hack." Where advocates were once viewed as "useless trouble makers," now "we see increasing acceptance of consumer action and—for the first time—even extensive consumer representation within agencies themselves."

Why desirable? "After all," says Diane Lattin, of the American Coalition of Citizens with Disabilities, "it is the disabled person who is really his own strongest advocate. Who is more believable than the disabled person who speaks to those who must know about what a disabled person can do?"

How does this jibe with the experience of the advocacy project site? Says Edwin Minter, executive of the Kansas City affiliate, "Advocacy, by the very nature of its process, should stress self-advocacy. It should teach it and encourage it."

Continues Minter, "I have no fear of such a program minimizing the roles of this agency. Rather, I suspect it will maximize our roles in other areas." And executive director Jane Chapin of Illinois, who also believes in stressing self-advocacy to the "maximum extent possible," adds that "incorporating this approach into our structure could strengthen UCP and other agencies."

The project site affiliates, their staffs and the advocacy coordinators have done what the National Advocacy Project asked of them—to test the advocacy approach pragmatically, to translate a concept and an idea and a credo into practical experience. To discover what works and what does not, the how-to's and the how-not-to's which have been incorporated in this report.

What is now done with the results of their efforts is for others to decide. Some affiliates may still need to convince themselves. The experiences and results achieved "need to be shown to those in doubt," says Margaret O. Murray. To "do advocacy," the affiliate will first need to be committed to advocacy.

Not only to the idea, but to its practical implementation. It is a commitment, says Mrs. Murray, which must reach up to and into every level of UCP.

It is a commitment, in theory and in practice, which must also be shared by individuals. "It becomes imperative to train both volunteers and staff people to become effective in this more sophisticated advocacy role."

Consumer commitment and training too. Advocacy is a concept and a credo, but advocating is an act and a skill. It can be taught; it can be learned. The projects have proven that.

"A Part Of Everything"

If the commitment is implemented, what can affiliates expect of advocacy?

Ernest Weinrich: It means giving the affiliates an additional tool, and without their having to spend a lot of money on it.

Marie Moore: Lots of affiliates are already involving consumers and modifying the system, even if they are also running into roadblocks. But there are others less ready. We have to raise their readiness level.

Weinrich: We have to say to them, why not begin to look at additional or different ways of helping people who have multiple disabilities?

Moore: In a sense, advocacy means going back to basics. Many voluntary agencies have now become vendors of service, but their original role was as advocates . . . In a way, it is going back to the earliest days of UCPA, when the parents who started it had to be advocates for their own infants and young children. Those babies are now 25- and 30-year-old adults and perhaps ready to be their own advocates.

Todd Eberle (Advocacy Coordinator, Illinois): Advocacy is going to be an injection into the total system at the affiliate level. The hope is that the injection will stimulate people who are not now advocates to become advocates. The advocacy coordinator may have to show people how, but that should be a temporary thing. He should not have to do it very long. Because advocacy is only a tool, a process, and not a goal or an end in itself.

The process? In part, reaching and teaching the consumer. In part, understanding and, where necessary, trying to change the service delivery system. In part, cementing more securely the partnership envisioned by the IHF Plan between UCPA and the disabled individual and his family.

The goal? On the immediate and practical level, helping the individual with cerebral palsy and other developmental disabilities to make the system more responsive to his needs, and to secure his rights.

But there is an even greater goal—helping the disabled individual to participate, to find added worth, independence, dignity and—with every new achievement—increasing fulfillment as a human being.

Not only to gain his rights. To regain his birthright.

Appendix A

STRENGTHENING THE PARTNERSHIP BETWEEN CONSUMERS* AND UCPA

Partners—the disabled individual and his "friend"—need to know exactly what the other can expect, exactly who will do what in response to any given situation and like a mature marriage, how the partnership can be improved.

Even though the United Cerebral Palsy Associations, Inc., has firmly embraced the concept of "partnership" through its "Individual with Cerebral Palsy and His Family" plan and programs, there is still a great deal of confusion among consumers concerning the partnership. Two reasons for this confusion result from a large number of persons actually representing the consumer through UPCA and the diverse standards of service among affiliates. The effect of these two circumstances means that UCPA is unable to make specific promises. Consequently, consumers reviewing UCPA literature and mass media presentations may have conflicting information from various sources—what you see and hear IS NOT usually what you get.

The National Advocacy Advisory Council of UCPA's Child Advocacy Project has identified the need for a policy statement from the National organization clarifying and outlining consumer involvement through UCP affiliates. The policy statement for consumers would help them to communicate needs and problems and foster participation in decision making bodies (boards, committees, task forces and council). Consumers could also act as affiliate representatives with other community, state or national organizations.

As recipients of services, consumers need to have a clear picture of what is available. It is proposed that each and every affiliate see that the following are offered for its community:

1. A definite service program with a basic program of information, referral and follow-along.

2. Communication with professionals working in service and consumer agencies so that these professionals can become knowledgeable about available or needed services for the developmentally disabled and make appropriate referrals.

3. A definite follow-through on referrals made to the UCP affiliate and follow-along on referrals made by the affiliate.

4. Community out-reach and case finding to inform consumers of services and programs available.

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*Consumer is defined as an individual with a developmental disability and his family.

5. A consumer information service using newsletters of UCPA and other provider agencies and consumer groups.

6. Encourage consumers already knowledgeable of services to spread the word to other consumers.

7. Inform the general public of services available, and use other public education methods relative to the needs of the consumers and methods of preventing developmental disabilities (e.g. Project Prevention).

The consumers in the partnership must have ways to participate in the decision making processes controlling their destinies. The following procedures are recommended in facilitating their involvement:

1. Strongly encourage professionals working in provider agencies to recruit people on their existing caseloads for participation on boards, councils, task forces, committees and any other bodies which set policies and priorities for services to the developmentally disabled.

2. Encourage involved consumers to spread the word to other consumers who might also be interested in serving in the above capacities.

3. Include statements in the bylaws of boards, councils, etc., which mandate that a certain substantial percentage of members be consumers reflective to the nature of the population served. The percentage should go beyond tokenism and involve substantial participation.

4. Recruit professionals and community leaders with developmental disabilities and other severe disabling conditions. Many may be employed in service agencies and can be easily located.

5. Request the involvement of consumers through contacts with various organizations including space in their newsletters.

6. Develop task forces or special interest groups—i.e. adult councils, parent councils, etc. These groups can be educational in nature for developing well-informed consumers and provide a forum for discussing issues and taking positive action.

7. Promote the representation of UCPA by consumers of the organization on such bodies as United Way Committees, Boards of Education, Headstart Programs, Day Care Centers and Community Service Programs.

We all learn from first-hand experience, through opportunities to participate directly in the formulation and execution of an idea or action. But when consumers are unable to gain access to these areas, frustration and isolation are compounded.

Through an interaction—a realignment of consumer expectations and a commitment to advocacy—persons with cerebral palsy will have an opportunity to enhance their own experiences and to be in a better position to complete the lifetime partnership.

Prepared and submitted by
the National Advocacy Advisory Council
March, 1974

Appendix B

EXPANDING UCPA'S ROLE AS ADVOCATE FOR HUMAN RIGHTS

"The handicapped individual has the right to petition social institutions and the court to gain such opportunities as may be enjoyed by others but denied the handicapped because of oversight, public apathy or discrimination."*

If this right is to become a reality for persons with cerebral palsy and other developmental disabilities, it must be supported with a plan of action by UCPA, Inc. In addition to its Washington Office focusing on governmental activities and the assignment of a representative on the Advisory Committee of the National Center for Law and the Handicapped, UCPA should **establish a Legal Advocacy Committee** which would develop mechanisms for legal action. The activities for such a committee should be planned for in the 1974-'75 budget.

One of the actions recommended would involve UCPA as Amicus Curiae (friend of the court) in highly selected cases in which the civil rights of citizens with developmental disabilities are at issue. The participation of UCPA in litigation would be after a plaintiff or class of plaintiffs with their attorney have initiated a case and this case is at the appellate stage—i.e. cases before a Federal Court of Appeals, the U.S. Supreme Court or the Supreme Court of states with large populations.

It is further recommended that UCPA, Inc., collaborate with other organizations through a common Amicus Counsel to maximize the impact of a particular counsel while reducing expenses for all participants. Consideration should also be given to the use of a public interest law firm or legal advocacy project which has already developed specialization in the area of legal rights of the physically and mentally handicapped (i.e. the Mental Health Law Project in Washington or the National Center for Law and the Handicapped in South Bend, Indiana). Under the recommendation, it would not be necessary to expand the role of UCPA's Corporate counsel.

Legal advocacy activities and rights litigation as Amicus Curiae has already occurred among other voluntary organizations—National Association for Retarded Citizens, Council for Exceptional Children, National Society for Autistic Children, National Association for Mental Health, American Association on Mental Deficiency and the American Orthopsychiatric Association.

Although many UCPA consumers have been served through the legal advocacy activities of these organizations, the legal rights of all consumers need to be examined and defended by UCPA itself.

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*Article X, "A Bill of Rights for the Handicapped," UCPA, Inc., May 4, 1973.

In addition to the role of Amicus Curiae in selected litigation, it is further recommended that a Legal Advocacy Committee be responsible for developing the following services:

1. Technical assistance to state and local affiliates in developing legal strategies for the consumers.

2. Technical assitance to attorneys of UCPA consumers in the identification, screening, recruitment or training of expert witnesses.

3. Technical assistance to state and local affiliates involved in informal legal negotiations.

Persons with developmental disabilities cannot be expected to gain a firm legal base for their rights without expert legal counsel. UCPA, like its counterparts, has a service opportunity through a legal advocacy approach incorporating legislation, litigation and legal negotiation. The specific recommendations outlined above would bolster the supportive legal services needed by persons with cerebral palsy and other developmental disabilities.

Prepared and submitted by the
National Advocacy Advisory Council
March 1974.

Appendix C

A CASE FOR THE ABSENT VOLUNTEERS

The National Advocacy Advisory Council (NAAC) of the UCPA's Child Advocacy Project has demonstrated through the involvement and composition of its volunteer memberships, that it is possible to establish a representative group reflecting the broad scope of concerns relative to the needs of the developmentally disabled. The composition of the council is multi-racial, multi-ethnic and multi-religious. The eleven women and six men range in age from 21-65 and represent expertise and experience in medicine, law, legislation, social work, physical therapy, psychology, education, management and consumer needs. Nine persons are either adults with cerebral palsy or parents of children with developmental disabilities and all represent a wide variation in income, education and social status.

Among the council's first recommendations to the project staff was the goal—"To promote and demonstrate an increased participation of people from racial and class groups usually not represented in planning and decision making." (Report of the National Advocacy Advisory Council Meeting—December 1-2, 1972.) The goal plus its objectives were later expanded for the project.

The National Advocacy Advisory Council believes that providers of service, community representatives and consumers have a right and responsibility to participate in determining the policies and practices of a voluntary agency. In the past, participation has been primarily limited to involving those who are affluent or hold positions in management which allows participation during business hours. Consequently, consumers and other community representatives who are not at a management level in business and industry have been excluded from participation in community services since they do not have the same privilege of time off with pay to exercise their community responsibilities.

A member of the National Advocacy Advisory Council, for example, found it difficult to accept membership on the council because she was the sole wage earner in her family. As a parent of a child with cerebral palsy, a recipient of UCP services and a member of a minority ethnic group, her experience and demonstrated involvement would allow for a significant contribution to the advocacy project and the National organization. Since she could not afford to lose the income for the time required to attend the council meeting, a letter requesting that she be allowed the time at company expense was sent to her employer.

The telephone response from the personnel manager was negative on the grounds that allowing one employee time-off with pay for "charitable" work would set a precedent that would be too difficult to manage.

Despite this decision of management, the commitment to service remained strong with the volunteer-consumer who made a personal sacrifice and accepted membership on the council.

Hundreds of people who could make significant contributions find it **impossible** to serve on boards, committees, task forces and councils. They are the **absent** volunteers whose contributions are missing from the problem solving/decision making processes.

The consumers of health and social services are viewed as the experts with profound knowledge and understanding of services from the users' points of view. These experiential points of view can bring exquisite sensitivity to agency program planning; yet, these viewpoints on the usefulness of service benefits and the area of unmet needs are often missing. Service delivery continues to be planned **for** and not **with** the very consumers it serves.

The National Advocacy Advisory Council recommends that the United Cerebral Palsy Associations, Inc., and its affiliates press business and industry to prepare and adopt a policy to allow UCPA and other consumers time off with pay to participate on national and local boards, councils, committees, task forces and advisory groups of voluntary and/or governmental organizations in accordance with policy applied to executives in order to broaden the participation of many socio-economic and ethnic groups; to enhance and extend the present substantial contribution of business and industry to the welfare of its workers and their community.

This recommendation is compatible with the continuing concern of business and industry for the welfare of its community and good public relations. It is also in line with present philosophy and practice of consumer involvement in the planning and direction of community services.

It is further recommended that any proposals and policies to be adopted by business and industry be reviewed with representatives of management, labor and organizations such as United Funds and governmental agencies to gain support for this effort.

The National Advocacy Advisory Council asks that UCPA, Inc., take a leadership role in creating this social change in eliminating arbitrary class distinction and privileges.

Prepared and submitted by
the National Advocacy Advisory Council
March, 1974.

Appendix D

NEW YORK STATE ADVOCACY MODEL

GOAL

To facilitate and initiate the program services needed by developmentally disabled persons and their families throughout New York State by working with local UCPA affiliates, Home Service Directors, State institutions, government agencies, voluntary agencies, state legislators and consumers.

OBJECTIVE A:

To prepare legislative proposals and promote legislation to meet the needs of the developmentally disabled in the State of New York.

RATIONALE:

Legislation in the State of New York for the multiply handicapped is inadequate, especially in the following areas:

1. Coordination of State's education, health, mental health, and social welfare programs so that a comprehensive continuum of services is provided for the developmentally disabled of all ages. There is a need for a single department, commission, or council with authority to implement such coordinated services within the State government.

2. Comprehensive educational programs, especially for children below the age of five and for those with multiple handicaps.

3. Vocational training and social adjustment programs.

4. Public transportation for the physically and mentally disabled.

5. Human rights—especially the rights to housing, recreation, transportation, employment, health services, education, and training.

6. Medical services which are geographically and economically accessible.

OBJECTIVE B:

To motivate and assist in the initiation of new programs and to seek improvement in and/or expansion of existing programs for the mentally, physically, and emotionally disabled in targeted areas of New York State, as determined by statistics on the existence of programs as

documented by the 1972 New York State Developmental Disabilities Council Report, local surveys and data, and the availability of funding sources.

RATIONALE:

The expansion and creation of new programs is necessary in order to fill service gaps for the developmentally disabled as they have been determined by local surveys and data, and by the 1972 New York State Developmental Disabilities Council Report.

OBJECTIVE C:

To promote the active involvement of consumers (disabled adults and parents) in the planning, policy-making and monitoring of services on a statewide and local level through their participation in the State Advocacy Council and at least four Local Advocacy Councils.

RATIONALE:

Program services established for the developmentally disabled should be responsive to the needs of consumers themselves as they define these needs. Too often services are developed to fill agency or professional needs without regard for consumers. As was documented in a 1971 survey of UCPA agencies, in recent years neither the disabled nor their parents have been significantly involved in the planning, policy-making and monitoring of services. By establishing and supporting consumer advocacy groups in targeted areas throughout the State, the Advocacy Project hopes to create a model that will be emulated by local affiliates. It also intends to support consumers in their efforts to make an impact on existing service delivery systems.

OBJECTIVE D:

To work with four targeted State institutions in planning strategies by which residents of the institutions may enter community based service programs for the disabled.

RATIONALE:

According to surveys made by the New York State Department of Mental Hygiene, more than one-third of the present residents in State institutions for the mentally retarded are capable of functioning independently or semi-independently in the community. The State institutions are over-crowded and their programming is inadequate to enable disabled persons to realize their potential for fulfilling lives as productive and independent citizens within a community. The goal of the State Department of Mental Hygiene and of many concerned voluntary agencies is to find educational, training, and employment programs in the community to which residents of institutions may be transferred. A corollary goal is the procurement of community based residential facilities (group homes, foster homes, hostels, etc.), so that the disabled person can **live** in a community at the same time that he goes to school or works in that community. At the present time, the number of community resources for residential facilities and day training programs is very limited, especially for persons with physical as well as mental handicaps. The Child Advocacy Project of UCPA of New York State intends to assist State institution staff in the maximum utilization of available community resources and in the development of additional needed programs in four targeted areas.

OBJECTIVE E:

To provide training and assistance to fourteen New York State Home Service Directors in the following areas: a) effective utilization of existing community resources, b) assisting individual clients and their families to exercise their rights to services as stated by law, and c) promoting the initiation of additional services for the mentally, physically and emotionally disabled.

RATIONALE:

The 14 Home Service Directors serve individual clients and their families in local communities throughout the state. A major part of their work consists of mobilizing and coordinating community resources to meet client needs and of intervening with community facilities in behalf of clients. In fulfilling these activities, Home Service Directors are functioning as local advocates. The Child Advocacy Project is focusing on providing training and information that will enhance the Home Service Directors' skills in obtaining and improving the services available to the developmentally disabled.

Appendix E

SAN MATEO-SANTA CLARA ADVOCACY MODEL

GOAL I:

To identify, describe and assess the targeted programs provided by public and private agencies for the developmentally disabled.

OBJECTIVE:

To determine the population served, purpose, duration, frequency, waiting period (if any), and eligibility requirements of each targeted service, as determined by the Local Advocacy Advisory Council (LAAC), that is provided by public and private agencies for the developmentally disabled in the target area.

RATIONALE:

The project needs readily accessible descriptions of what services are available and how they are used by consumers.

GOAL II:

To describe and evaluate differences in and barriers to the utilization of services by families with children who are developmentally disabled.

OBJECTIVE:

To develop comparative data regarding differences in and barriers to the service delivery system as it relates to high and low income and ethnic groups in the two-county area.

RATIONALE:

Preliminary investigations have identified several barriers to services for the developmentally disabled related to income and ethnicity: for example, (1) some agencies have maximum income eligibility requirements; (2) some have minimum income eligibility requirements (e.g. they automatically refer AFDC eligible families to public welfare agencies); (3) some agencies have few Spanish speaking personnel; and (4) the limited public transportation services in the two counties makes it more difficult for families without private transportation during working hours to reach some agencies for service.

GOAL III:

To identify services needed and/or changes sought in the service delivery system from the consumer's perspective.

OBJECTIVE:

To develop data which will enable the coordinator and local advocacy advisory council to focus project efforts on service delivery problems of the consumers in the target area.

RATIONALE:

The project is oriented toward consumer views of service delivery. The consumer with the appropriate resources can provide the most useful information regarding his diverse needs and problems.

GOAL IV:

To strengthen and increase the participation of a diversity of consumer groups and individuals in the planning and delivery of services for developmentally disabled children and their families.

OBJECTIVE:

To increase the number of young and/or poor and/or ethnic minority consumers who are members of two principal targeted planning units for the developmentally disabled in the target area:

1. The San Mateo Coordinating Council on Developmentally Disabled

2. The Santa Clara County Advisory Commission on Developmentally Disabled.

RATIONALE:

Younger, poorer, and more ethnically diverse consumers have been traditionally excluded from direct representation on planning units of provider agencies.

OBJECTIVE:

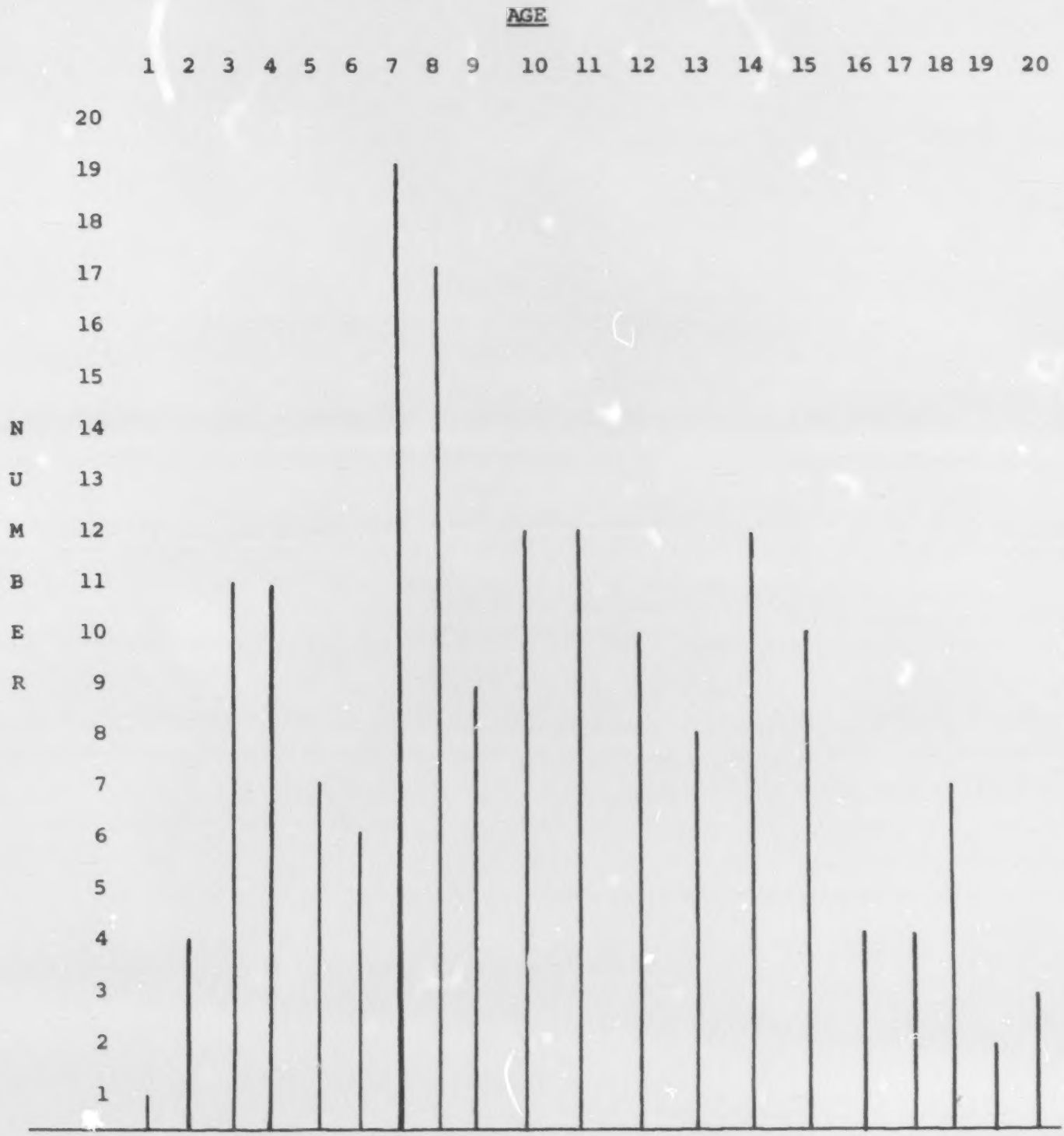
To develop and implement programs to increase the advocacy functions of groups of consumers in the target area.

RATIONALE:

Four predominant methods of advocacy have been used in support of the needs of the developmentally disabled: (1) Community action by voluntary health associations and in some public agencies; (2) Case advocacy by professionals in agencies providing services; (3) Legislative advocacy; and (4) Litigation. Advocacy by groups of consumers is another method which will supplement these four in making the service delivery system more responsive to the diverse consumer population.

Appendix F

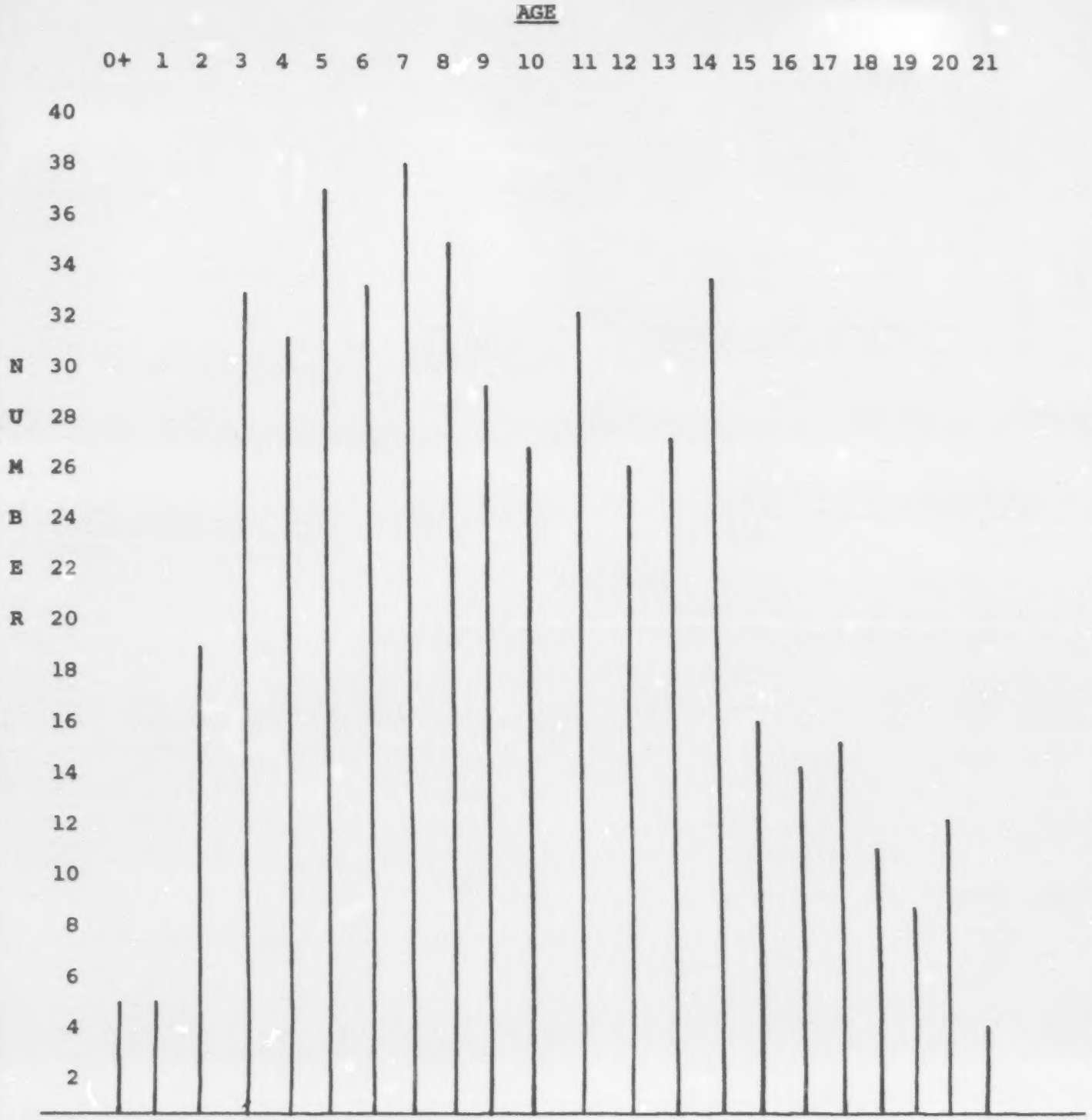
AGES OF CEREBRAL PALSIED CHILDREN
IN ACTIVE CASE REGISTRY OF
SAN MATEO COUNTY CRIPPLED CHILDREN'S SERVICE



Source: Case Register of San Mateo County Crippled Children's Service
(Counted 1/31/73)

Appendix G

AGES OF CEREBRAL PALSIED CHILDREN
In Caseload of Santa Clara County Crippled Children Service



Source: Santa Clara Public Health Department, Statistics Office as of 12/31/72.

Appendix H

FINDING HELP FOR A DISABLED CHILD IN SANTA CLARA COUNTY

Many parents have expressed concern about where to get help for a child that is developing slowly, due to serious health problems or handicaps. There are many services designed specifically to help the disabled child develop to his fullest abilities.

This brochure was prepared by representatives of several public and private agencies for the mentally retarded and physically handicapped in Santa Clara County. Its purpose is to provide information to which parents can refer when they need help.

● WHAT ARE THE AGENCIES YOU CAN CALL FOR HELP?

The county **Health Department** provides a variety of services from which your child and family may benefit. Two of these are Public Health Nursing and Crippled Children's Services.

A public health nurse will visit you in your home and help determine the health needs of your family. She can assist you with these needs through counseling, home demonstration, teaching basic health concepts and referrals to appropriate public and private health agencies.

Crippled Children's Services provides diagnostic examinations and treatment for physically handicapped children from birth to twenty-one years of age. Many severe, chronic or disabling physical handicaps are eligible for services: cerebral palsy, heart disease, ear conditions leading to the loss of hearing, etc. The diagnostic services are free. Financial assistance is available for the purchase of treatment services to those who are eligible.

Call your local Health Center, or 297-1636 to determine the closest Health Center that serves your neighborhood.

The county **Department of Social Services** coordinates a countywide referral service to help you find the right place to get help. Spanish speaking operators are available. Any person may ask for information by calling 299-4041.

The Department also provides financial help to families in need. A family may call their eligibility worker and ask that a "service referral" be made if they want help for a child who seems slow, retarded, or having difficulties in getting along, compared to other children of the same age.

The **Loma Prieta Regional Center for the Developmentally Disabled** is an agency which provides diagnosis and evaluation as well as counseling services. A counselor is assigned to help you handle any problems. Assistance is available to help find and purchase services. Call 275-8590.

● WHERE CAN YOU CALL FOR MEDICAL CARE OR EXAMINATION TO LEARN MORE ABOUT YOUR CHILD'S CONDITION?

1. Contact your private medical doctor.
2. Public Health Department –
   Call your local Health Center for a public health nurse who will arrange for an examination through Crippled Children's Services and/or other referrals.
3. Department of Social Services –
   Call your social worker or eligibility worker. If you don't have one, call or visit your local Welfare office. **Everyone is eligible to receive these services.**
4. Loma Prieta Regional Center For The Developmentally Disabled –
   235 East Santa Clara, San Jose – 275-8590

● WHAT IS AVAILABLE FOR THE VERY YOUNG HANDICAPPED CHILD?

Before school your child may attend an Infant Program (for birth to 3 year olds) and/or a preschool program (for 3-6 years old).

- An Infant Program sometimes provides classes for the parent and baby. There are also programs to teach the mother and father how to become a teacher of their child. Activities are provided which help the baby to develop physically, socially, and intellectually.

- If your child is between the ages of 3-6 years, he may attend a preschool class for up to five days a week. Preschool classes provide activities for handicapped children to learn daily living tasks, enjoy the pleasure of other children and learn to communicate with others. These programs invites parents to evening discussion groups.

- Ask your social worker, public health nurse or Loma Prieta Regional Center counselor for more details.

● WHAT ABOUT SCHOOLS?

Special programs are available for handicapped children. Some of these programs are operated by individual school districts and others by the office of the County Superintendent of Schools.

For more information, contact the principal of your neighborhood school.

● WHAT ABOUT BABYSITTERS, DAY CARE AND TEMPORARY CARE?

At times, you may need temporary weekend or vacation care for the mentally retarded or physically disabled child. Agencies sometimes call this respite care. Contact either the county Department of Social Services or the Loma Prieta Regional Center for information.

If you need help in finding care on a regular basis while you work, or if your regular babysitter is not able to care for your handicapped child, contact the Department of Social Services or the Loma Prieta Regional Center about licensed day care homes, nurseries or other daily programs.

● WHAT ABOUT OUT-OF-HOME PLACEMENT?

If you are interested in obtaining information, for use now or in the future, concerning out-of-home placement, contact the county Department of Social Services or the Loma Prieta Regional Center. They can help you plan for your child's care. There are a variety of possibilities you may consider: licensed residential homes, schools and state hospitals. Since the selection of a specific place is based on the needs of the disabled person and the wishes of his family, you should feel free to discuss your situation with these agencies.

● WHO CAN WE CALL FOR RECREATION AND SOCIAL ACTIVITIES?

Many community recreation departments throughout the county offer programs for handicapped children and adults. Activities include field trips, arts and crafts, day camps, swimming and sporting events, drama, cooking, dances and special events: for more information contact your local parks and recreation department or school district.

Some libraries offer special programs for the handicapped. Contact your city's public library for information concerning talking books, mobile library services and braille books.

● WHERE CAN YOU GET INFORMATION ABOUT PARENT GROUPS?

If your child attends a special education program, call the school for information about its parent group. These organizations can provide an opportunity for you to talk to and compare experiences with other families facing similar problems.

Parent groups can also be very influential forces when they act as advocates for their children. Your active participation can help bring about change so that the services can be more complete.

The following voluntary associations conduct a variety of programs for handicapped children and adults with active parent groups:

Central Santa Clara County Aid to Retarded Children
P. O. Box 465, Cupertino

Community Association for the Retarded
3864 Middlefield Road, Palo Alto - 494-0550

Hope for Retarded Children and Adults, Inc.
2300 Clove Drive, San Jose - 295-1065

Santa Clara Epilepsy Society
P. O. Box 5214, Santa Clara

United Cerebral Palsy Association of Santa Clara County
P. O. Box 4161, Mountain View - 293-2777

● HOW DOES THE HANDICAPPED PERSON FIND A JOB?

The California State Department of Rehabilitation provides services to any man or woman with a physical or mental handicap which interferes with his ability to find work. The rehabilitation services enable the individual to secure gainful employment. Services include diagnostic services, counseling and guidance, training including personal and vocational adjustment, physical restoration, placement and follow-up services. Any handicapped person seeking work may apply to the nearest office of the Department of Rehabilitation by mail, telephone or personal visit. Offices in Santa Clara County are located at 935 Ruff Drive, San Jose: 1575 E. Santa Clara, San Jose and 455 Sherman Avenue, Palo Alto.

● HOW CAN YOU GET FINANCIAL HELP?

- Money is available from the Social Security Administration to some disabled people of any age. For more information, call 263-3930 and ask about Supplemental Security Income (SSI) program.
- Other financial help is available through the Department of Social Services to some families because of their need for food, shelter and clothing. Call 299-1121 or go to the nearest office for more information.

● WHO PLANS FOR THE DISABLED IN SANTA CLARA COUNTY?

An Advisory Commission for the Developmentally Disabled annually develops a county plan for services and advises the Board of Supervisors about needs. The Commission sponsors the Developmentally Disabled Services Forum. This is a monthly meeting for people providing service and for families of the disabled. Parents are encouraged to attend these meetings to express their concerns and help improve programs in future years. Call 299-2323 for meeting dates and times.

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It is important to be persistent in your efforts to find the agencies and services that can be most helpful to you. Perhaps your initial contact may not be the most appropriate to your individual needs. **Don't become discouraged!** Your efforts will directly benefit your child.

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Appendix I

COMO ENCONTRAR AYUDA PARA UN NIÑO INCAPACITADO EN EL CONDADO DE SANTA CLARA

Muchos padres han expresado su preocupación, porque no saben dónde conseguir ayuda para un niño de lento desarrollo debido a problemas serios de salud o a limitaciones físicas. Hay muchos servicios especialmente diseñados para ayudar al niño a conseguir el máximo desarrollo de sus capacidades.

Este folleto fué preparado por los representantes de varias agencias públicas y privadas, dedicadas a la atención de retardados mentales e inválidos en el Condado de Santa Clara. Su propósito es el de proporcionar información a los padres que necesitan ayuda.

• ¿CUALES SON LAS AGENCIAS A LAS QUE USTED PUEDE PEDIR AYUDA?

El Departamento de Salud Pública del Condado de Santa Clara proporciona una variedad de servicios que pueden ser aprovechados por su niño y su familia. Dos de ellos son: los servicios de Enfermeras en Salud Pública, y los Servicios para Niños Lisiados.

Una enfermera en salúd pública visita a usted en su casa, y le ayuda a reconocer las necesidades de salud de su familia. La enfermera le puede dar consejo, hacer demostraciones en el hogar, enseñar conceptos básicos de salud, y le orienta para la utilización apropiada de agencias de salud públicas o privadas.

El Servicio para Niños Lisiados (Crippled Children's Services) proporciona exámenes para diagnóstico y tratamiento, desde recién nacidos hasta los veintiún años de edad. Aquellas personas que padecen incapacidad o limitaciones físicas severas o crónicas, son elegibles para obtener los servicios: parálisis cerebral, enfermedades del corazón, enfermedades del oído que conducen a la sordera, etc. Los servicios de diagnóstico son gratis. Se puede obtener ayuda económica para el pago de servicios de tratamiento, para aquellas familias que lo necesiten y sean elegibles.

Llame a su Centro de Salud local o al 297-1636, para pdeir información sobre el Centro de Salud más cercano a su domicilio.

El Departamento de Servicios Sociales del Condado de Santa Clara (Department of Social Services), coordina un servicio de orientación que abarca todo el Condado, y que puede ayudarle a encontrar el lugar preciso donde puede usted obtener la ayuda que necesita. Cualquier persona puede pedir información llamando al 299-4041. Las telefonistas en servicio hablan español.

El Departamento también proporciona ayuda en dinero a familias que lo necesiten. Las familias pueden llamar al empleado que se ocupa de ver si pueden recibir servicios (Eligibility Worker), y pedirle que haga un "servicio de canalización" ("service referral"), si desean ayuda para un niño que parece lento, retrasado, o con dificultades de aprendizaje, comparado con otros niños de su misma edad.

El Centro Regional de Loma Prieta para los Incapacitados en su Desarrollo (Loma Prieta Regional Center for the Developmentally Disabled), es una agencia que proporciona diagnóstico y evaluación, lo mismo que servicios de consejo. Un experto le ayudará a buscar soluciones para sus problemas. Hay manera de conseguir ayuda para el pago de los servicios. Llame al 275-8590.

• ¿DONDE PUEDE USTED LLAMAR PARA LA ATENCION O EXAMEN MEDICO DE SU NIÑO QUE LE PERMITA CONOCER MEJOR SU ESTADO?

1. Hable con su médico privado.
2. Departamento de Salud Pública –
   Llame a su Centro de Salud local para que una enfermera en salud pública haga arreglos para un exámen a través de los Servicios para Niños Lisiados (Crippled Children's Services) o en otras agencias.
3. Departamento de Servicios Sociales –
   Llame a su trabajador social o su "eligibility worker". Si usted no tiene uno, llame o visite su oficina local de Welfare. **Cualquiera es elegible para recibir esos servicios.**
4. Centro Regional de Loma Prieta para los Incapacitados en su Desarrollo (Loma Prieta Regional Center for the Developmentally Disabled) –
   235 E. Santa Clara, San José - 575-8590

• ¿QUE SERVICIOS HAY PARA UN NIÑO MUY PEQUEÑO?

Antes de la edad escolar, su niño puede ir al Programa para Infantes desde recién nacido hasta los tres años de edad, y de los tres a los seis años puede acudir al programa pre-escolar.

- El Programa para Infantes a veces dá clases para los padres y para el bebé. También hay programas especiales para enseñar tanto a la madre como al padre cómo poder ser maestros de su propio hijo. Hay actividades para ayudar al niño en su desarrollo físico, social y mental.

- Si su niño tiene entre tres y seis años de edad, puede acudir a las clases para pre-escolares, que se imparten de lunes a viernes. Estas clases ayudan a que los niños incapacitados aprendan cosas de la vida diaria, gocen de la compañía de otros niños, y aprendan a comunicarse con los demás. Hay reuniones de grupos en las noches, para padres.

- Pregunte a su trabajador social, enfermera en salud pública, o al consejero en el Centro Regional de Loma Prieta, para más detalles.

• ¿QUE ESCUELAS HAY?

Hay programas especiales para niños incapacitados. Algunos programas dependen directamente del distrito escolar, y otros, de la oficina de la Superintendencia de Escuelas del Condado de Santa Clara. Para mayor información, hable con el director de la escuela más cercana a su domicilio.

• ¿QUE HAY PARA EL CUIDADO DIARIO O TEMPORAL DEL NIÑO?

Algunas veces, usted podrá necesitar a alguien que le cuide a su niño retrasado mental o incapacitado, durante un fin de semana o unas vacaciones. Las oficinas le llaman "atención de respiro". Pida información al Departamento de Servicios Sociales del Condado o al Centro Regional de Loma Prieta.

Si usted necesita ayuda para que alguien cuide a su niño en forma regular mientras usted trabaja, o si la persona que siempre lo cuida no puede hacerlo, llame al Departamento de Servicios Sociales o al Centro Regional de Loma Prieta, para informarse sobre guarderías infantiles, hogares substitutos, y otros programas de atención en el día.

• ¿DONDE ALOJAR AL NIÑO FUERA DEL HOGAR?

Si le interesa información--ya sea para ahora mismo o para el futuro--sobre hospedaje fuera de la casa, llame al Departamento de Servicios Sociales del Condado, o al Centro Regional de Loma Prieta. Ellos pueden ayudarle a planear el cuidado de su niño. Hay varias posibilidades: hogares substitutos autorizados, escuelas, o bien, hospitales del Estado. La selección del lugar se debe basar en las necesidades de la persona incapacitada y los deseos de su familia. Sienta la libertad de discutir su problema con estas agencias.

• ¿A QUIEN LLAMAR PARA RECREACION Y ACTIVIDADES SOCIALES?

Muchos departamentos de recreación para la comunidad por todo el Condado, ofrecen programas para niños y adultos impedidos. Dichas actividades incluyen visitas de campo, artesanías, excursiones, natación y otros deportes, actuación, cocina, danza y otras actividades. Para mayor información llame al Departamento local de Parques y Recreación, al distrito escolar.

Algunas bibliotecas ofrecen programas especiales para los incapacitados. Visite la biblioteca pública de la ciudad, para informarse sobre libros narrados, la biblioteca móvil, y los libros de Braille para ciegos.

• ¿DONDE PUEDE INFORMARSE ACERCA DE GRUPOS PARA PADRES?

Si su niño asiste a un programa de educación especial, llame a la escuela para que le informen acerca de los grupos para padres. Estas organizaciones dan oportunidad para que los padres puedan hablar y comparar sus experiencias con otras familias que tienen el mismo problema.

Los grupos de padres también poder para actuar en defensa y beneficio de sus hijos. Su participación activa puede lograr cambios para que los servicios ofrecidos sean más completos.

Las siguientes asociaciones voluntarias tienen programas para niños y adultos incapacitados, con participación activa de los padres:

Central Santa Clara County Aid to Retarded Children
P.O. Box 465, Cupertino

Community Association for the Retarded
3864 Middlefield Road, Palo Alto - 494-0550

Hope for Retarded Children and Adults, Inc.
2300 Clove Drive, San Jose - 295-1065

Santa Clara Epilepsy Society
P.O. Box 5214, Santa Clara

United Cerebral Palsy Association of Santa Clara County
P.O. Box 4161, Mountain View 293-2777

• ¿COMO PUEDE ENCONTRAR TRABAJO LA PERSONA INCAPACITADA?

El Departamento de Rehabilitación del Estado de California proporciona servicios a cualquier persona cuya incapacidad física o mental interfiera en la obtención de un trabajo. Los servicios de rehabilitación ayudan a capacitar a la persona para la obtención de un trabajo. Los servicios de rehabilitación ayudan a capacitar a la persona para la obtención de un empleo remunerativo. Los servicios incluyen: diagnóstico, consejo y guía, entrenamiento tomando en cuenta ajuste personal vocacional, rehabilitación física, servicio de colocación, y asesoría posterior. Cualquier persona impedida que desee encontrar empleo debe hacer su solicitud a la oficina mas próxima del Departamento de Rehabilitación, ya sea por correo, por teléfono, o visitándola personalmente. Las oficinas en el Condado de Santa Clara se encuentran en 935 Ruff Drive, en San José; 1575 E. Santa Clara, en San José, y 455 Sherman Avenue, en Palo Alto.

• ¿COMO PUEDE USTED OBTENER AYUDA ECONOMICA?

Hay dinero disponible para algunas personas incapacitadas en la Administración de Seguridad Social (Social Security Administration).

• ¿QUIENES PLANEAN PARA AYUDAR A LOS IMPEDIDOS DE SANTA CLARA?

Cada año una Comisión de Expertos en el Desarrollo de los Impedidos trabaja en un plan general para el condado, para los servicios, y aconseja al Consejo de Supervisores acerca de cuales son las necesidades. La Comisión patrocina el Foro de Servicios para Impedidos en su Desarrollo (Developmentally Disabled Services Forum) donde mensualmente se reúnen las personas que prestan servicios para los impedidos, y las familias de los mismos. Se anima a los padres de niños impedidos a asistir a estas reuniones, para que expresen sus opiniones que lleven al mejoramiento de los programas en el futuro. Llame al teléfono 299-2323 para que le informen de la fecha y la hora de las reuniones.

Es importante que persista en sus esfuerzos para encontrar las agencias y servicios que puedan ser de mayor ayuda para usted. Probablemente su contacto inicial no sea el más apropiado para sus propias necesidades. No se desanime! Sus esfuerzos beneficiarán directamente a su niño.

Appendix J

Position Statement

EARLY IDENTIFICATION AND PROGRAMMING: BARRIERS TO REFERRAL AND SERVICE DELIVERY SYSTEMS

Current statistics show that one child in 16 may have a birth defect; and quite naturally, parents of these children with possible developmental problems are asking recurring questions:

- "Will my baby be all right?"
- "What can be done for my baby?"
- "What is the future for my child?"

And answers from consulting professionals continue to be varied:

- "Let's wait and see how he progresses. He may out-grow these problems."
- "It would be best if you make plans for the child to be placed in an institution."
- "With the number of problems your child has, he does not fit into the programs we have established."
- "Take your baby home and love her. There is not much we can do now but let's have another look at her in six months."
- "We will be working with you and your child so that we can correct **some** of his problems and help in his development."

Once parents have heard the last answer and begin to participate in special infant programs, they often remember the other responses, those negative responses which gave parents no direction and engendered feelings of despair or puzzlement. Many parents have not heard the last response and either continue their search for a better answer or succumb to the finality of an earlier recommendation.

There is a continuing concern by the consumers and providers of services who belong to UCPA's National Advocacy Advisory Council for those children with developmental disabilities and their families not receiving early identification and programming. Even when early problems are identified, there is often a critical lag before the child receives services.

A number of problems have been identified by parents as **barriers** to service delivery systems which should provide early identification and programming. These problems include the following:

1. Maldistribution of pediatricans, neonatoligists and public health specialists who are qualified to give useful guidance.

2. Lack of knowledge among primary physicians in family practice and pediatrics concerning treatment facilities, pre-school programs and other helpful resources in their geographic area.

3. Lack of universal coordination among medical, allied health and child development specialists for the dissemination of their bodies of knowledge to be used in community based medical services.

4. Lack of a delivery system offering continuity of care, periodic monitoring and reassessment to safeguard the developmental potential of the infant who has been identified as "at risk."

Because the physician is frequently the first **professional** person to identify the problems of a developmental disability, he or she is in the position to initiate case management services. However, many primary physicians do not refer their patients to specialists and special programs because they lack a knowledge about developmental disabilities and community resources.

The National Advocacy Advisory Council asks that the United Cerebral Palsy Associations, Inc., consider the following recommendations in order to help eliminate many of the existing barriers in referral delivery systems:

1. **Establish a coalition** among UCPA, Inc., with the Academy of Pediatrics and Academy of Family Practice and the American Academy of Cerebral Palsy and the National Medical Association, for the purpose of supporting a number of training workshops focusing on the referral needs of individuals with developmental disabilities and their families.

2. **Prepare an audio-visual presentation** for physicians and other professional personnel demonstrating the model process of early identification, referral and follow-along. This presentation should include the following material:

   a. The **relationship** between the concerned family and the primary physician including the emotional impact faced by families and support needed from the primary physicians. The portrayal of family reaction is essential to the future of the parent/child relationship.

   b. The involvement of the primary physician in referring the individual and his family to appropriate specialists and early treatment-education programs.

   c. The follow-along responsibilities of the primary physician.

   d. The research findings that are utilized by the service specialists that are the rationale for early identification and program services.

e. The utilization of medical, allied health and other professionals in the total service delivery system.

f. Alternative choices for referral to existing programs when there is a lack of a community resource.

g. The partnership that should be formed among physicians, parents, a UCP local or state affiliate and other agencies when resources need to be developed.

3. **Develop Guidelines** for affiliates to initiate leadership in the fulfillment of their responsibility in establishing cooperative relationships with physicians and other professionals relative to early case findings, early programming and other unmet needs of children with developmental disabilities.

4. **Establish training programs for affiliate staff** focusing on cooperative relationships with the medical community in the development and implementation of a developmental model of comprehensive service in their communities. The program content would include guidelines for developing valuable community resource files for physicians in family practice and pediatrics. The Professional Services Program Committees of the affiliates should be actively involved in workshop planning.

Appendix K

PROJECT PROPOSAL

Title of proposed project: **Early Identification and Referral of Suspected Developmentally Disabled Children in Santa Clara County**

Specific Goals and Objectives of This Project

The first objective is to increase the early identification and referrals of developmentally disabled or suspected developmentally disabled children under four years of age to appropriate diagnostic services, i.e. Loma Prieta Regional Center, Crippled Children's Service of Santa Clara County or Santa Clara County Child Development and Diagnostic Clinic.

The secondary objective is to develop and demonstrate an early identification and referral model via the activities of a concentrated coalition (Early Identification and Referral Coordinators, consumers and relevant agency representatives). This model will be established on a continuing basis in Santa Clara County and will be available for replication in other California Counties.

Other activities of an Early Identification and Referral Project would focus on a portion of the county with a high proportion of low income and Chicano households—the East Valley District (that portion of the metropolitan area east of Highway 101 and particularly the Alum Rock District):

- Fifty doctors offices located in the East Valley
- Public Health Nursing serving six child health conferences
- Nineteen licensed day care centers in East Valley
- Project Impact (four Associations for Retarded Children have employed a neighborhood outreach worker to involve the low income Chicano families with retarded children in the Alum Rock Area)
- A committee of agency staff and consumers that has been meeting for several months to consider ways of bridging the gap between the Chicano community and the agencies providing services to developmentally disabled children.

We decided to focus on the East San José area, therefore, for the following reasons: 1. It is an area of high incidence of poverty and with many minority families on which we have accumulated data. 2. It is an area where many families, in the judgment of other professionals, do not see physicians regularly. 3. We had already established relationships with public health nursing and other community and professional leaders, to whom the early identification and referral coordinator would be readily introduced.

Methods and Procedures to be Used to Achieve Project Goals

A Policy Committee, advisory to the Early Identification and Referral Project, will be formed composed of two parents of developmentally disabled preschool children, a pediatrician, a public health nurse, a representative from Loma Prieta Regional Center, the Child Services Coordinator of UCPA of Santa Clara, representatives from relevant agencies and consumer groups. This Committee will advise on the hiring of staff, will review Project progress, and will assist in the evaluation of the impact of the Project on the service delivery system and will determine methodology for continuation of the effort after the conclusion of the demonstration project.

The services of a research/evaluation consultant will assist in the measurement of Project effectiveness in terms of increased referrals and changed referral patterns, the cost benefit of various Project activities and the appraisal of the impact of the Project activities on the service system. The research/evaluation consultant will assist in the preparation of the final report.

United Cerebral Palsy Association of Santa Clara County will employ two (2) Early Identification and Referral Coordinators half time for a period of six months—to implement a strategy of early identification and referral of 0-3 year old suspected developmentally disabled children to appropriate diagnostic services. The Early Identification and Referral Coordinators will be administratively responsible to the Child Services Coordinator of UCPA. The professional judgment and competence of the Early Identification and Referral Coordinators (with qualifications in public health nursing and/or as pediatric nurse practitioners) will shape the specific strategy to be implemented. The general strategy will include coordination with the following:

A. Consumers
B. Physicians
C. Hospitals
D. Public Health Nurses
E. Department of Social Services
F. Day Care Centers

It is anticipated that a six month effort, enlisting the cooperation of a variety of health and social service agencies and community groups, can increase the likelihood of early intervention for 0-3 suspected developmentally disabled children. The Project can provide data on the impact of such a concentrated coalition effort which leads to a continued effort in Santa Clara County and replication elsewhere.

Plans for Continuing Services After Project Ends

Essentially the Project is a demonstration of a concentrated coalition effort by consumers and members of several public and private agencies to increase the number of referrals of suspected developmentally disabled children under ages 0-3 to the appropriate diagnostic services in Santa Clara County. Continuation may take several forms:

A. The Policy Committee to the Early Identification and Referral Project will include members of the Early Childhood Task Force of the Santa Clara Developmental Disabilities Services Forum, a continuing organization in Santa Clara County. Learnings from the Project, in terms of effective methods to increase identification and referrals, and

materials developed in the course of the Project will assist this Task Force in continuing the efforts to identify, refer and serve young D.D. children.

B. The assignments of staff members of the Regional Center, Crippled Children's Service, and the UCPA may be changed to include some of the functions performed by the Early Identification and Referral Coordinators during the Project period. Staff assignment changes will be evaluated by members of the Project Policy Committee and by UCPA of Santa Clara within the year following the conclusion of the Project.

C. The activities and final report of the Early Identification and Referral Project will generate information about the problems of early identification and referral as well as possibilities for improved early intervention in Santa Clara County. This information could lead to the establishment of a comprehensive and continuing program of early identification and referral for developmentally disabled children.

Appendix L

MILWAUKEE ADVOCACY MODEL

GOAL I:

To actively promote and support the participation of the consumer and consumer groups concerned with the developmentally disabled in the determination and development of needed services, and in the monitoring of existing services to the developmentally disabled in order to enable the consumer to become an advocate for his own interests and to establish a framework within which the consumer can participate effectively.

RATIONALE:

The consumer has the greatest degree of involvement with the problems and has the best understanding of the impact of those problems on the developmentally disabled individual and family.

OBJECTIVE A:

To develop consumer awareness of the policies and functions of the project, the advocacy advisory council, and to involve consumers in project activities.

OBJECTIVE B:

To increase consumer effectiveness in advocating for improvement in the service delivery system for the developmentally disabled by increasing consumer participation and influence within the system.

GOAL II:

To provide a channel for cooperative effort on the part of consumers, community representatives and provider agencies.

RATIONALE:

As pointed out in a number of studies, there has been a long history of non-cooperation between provider agencies, resulting in duplication of services, competition between agencies for resources and clientele, fragmentation of services, and lack of agency accountability and responsiveness.

OBJECTIVE A:

To increase, through the Advocacy Advisory Council, cooperation and coordination among service providers, between service providers and consumers, and between service providers and community representatives to reduce competition and minimize fragmentation of services among service providers.

OBJECTIVE B:

To influence, through the Advocacy Advisory Council, the delivery of services to achieve comprehensive and quality services for the developmentally disabled.

GOAL III:

To improve the adequacy and appropriateness of both private and public services to the developmentally disabled.

RATIONALE:

As documented by existing reports and surveys, services to the developmentally disabled are inadequate. Many areas of significant need are not being met by the existing service system.

OBJECTIVE:

To develop and conduct an ombudsman program which will advocate for improvement in the availability and delivery of services to the developmentally disabled.

GOAL IV:

To monitor and initiate and influence legislation affecting the developmentally disabled.

RATIONALE:

Legislation is the greatest single influence affecting the provision of service to developmentally disabled persons. The authority, responsiblity and funding of services are most often vested in legislative mandate.

OBJECTIVE:

To continuously monitor and influence legislative action which affects the developmentally disabled.

THE DD SPOKESMAN
DEVELOPMENTAL DISABILITIES SPOKESMAN

1415 Wauwatosa Avenue, Suite 100 Milwaukee, Wisconsin 53213
Vol. 1, No. 3 August 1973

WISCONSIN LEGISLATION

The following is a very brief, simplified description of how a bill becomes law in Wisconsin. Please note that "point" and "counterpoint" indicate alternative actions that may take place at those times.

A bill is the product of the legislator's own thought, the thoughts of citizens, citizen's groups, or state agencies.

The Legislative Reference Bureau (LRB) prepares the bill in the proper form for introduction into the house of origin (Senate or Assembly). The bill is then ready for the first reading.

FIRST READING OF A BILL: At this point the proposal is introduced and given a number by the chief clerk in the house of origin. The chief clerk reads the title of the proposal to the house and gives it a number, such as 1973 Assembly Bill 300. The presiding officer refers it to the appropriate standing committee.

The most important committee of the Wisconsin legislature is the Joint Finance Committee. Any proposal involving the expenditure of state funds must, prior to its final passage, be referred to the Joint Committee of Finance for review.

COMMITTEE ACTION: The rules of the Wisconsin Legislature provide for public hearings and most bills are publicly aired. Anyone may usually sit in on a hearing.

FISCAL NOTES: Wisconsin rules require that all proposals which increase or decrease the revenue or costs of state government must carry a fiscal note. These notes discuss the effect of the proposal on the finances of the state.

WITHDRAWING A BILL FROM COMMITTEE: *Point:* The Assembly requires a two-thirds vote during the first 21 calendar days to withdraw a bill from committee. *Counterpoint:* After 21 days, if the committee has not reported on the proposal, the Assembly can withdraw the bill by a simple majority.

The Senate provision for recalls of a bill is less specific. *Point:* By precedent, the Senate may recall a bill from committee at any time by a majority vote. *Counterpoint:* Should the initial Senate motion to recall a measure fail, then subsequent motion to recall the same measure requires a two-thirds vote.

SECOND READING OF A BILL: The Chief Clerk reads the Standing Committee's recommendations to the members when the presiding officer announces "Reports of Standing Committees". After the committee report is read, the bill is placed on the calendar two days later under the heading of "Second Reading and Amendmendments of Bills".

At this stage in the legislative process, the merits of the bill are debated and it is open to amendment.

Next the members vote as to whether the bill should be engrossed (put the original proposal with its approved amendments and technical corrections in proper sequence at the time the bill was ordered engrossed) and read a third time. When the amendments have been debated, the members vote on the adoption of any amendments.

THIRD READING OF A BILL: If a bill is ordered engrossed and read a third time, it is automatically referred to the engrossing clerk who, under the direction of the Chief Clerk, incorporates whatever amendments have been adopted and checks that all amendments properly fit into the proposal. A proposal found to be correctly engrossed is placed on the calendar two days later under the order of business "Third Reading of Bills". *Point:* At this time the bill is no longer open to amendment. *Counterpoint:* It is still open to debate.

When the debate is over, the presiding officer asks the members, "This bill having been read three times, shall the bill pass?" *Point:* Approval by a majority of those voting allows the bill to pass on to the other house. *Counterpoint:* Motion to reconsider. After the bill was either engrossed, indefinitely postponed, passed or failed to be passed, any member can move to reconsider that particular vote, IF he voted with the majority which carried the question. It is at this point that many votes are reversed and bills that might have been killed come to life again. This motion must be made on the same legislative day immediately following the vote or on the next succeeding legislative day on which any roll call is taken.

ACTION BY THE OTHER HOUSE: Assuming that the bill has now passed the Assembly (1973 Assembly Bill 300), it must be sent to the Senate where it undergoes further extensive examination quite similar to that which the Assembly has already given it. The bill is given Senate committee consideration; it is debated on the floor of the Senate where it might possibly be amended further; and finally if it is the type of bill that the legislators think will make a good law.... *Point:* The bill is passed. *Counterpoint:* If the second house has amended the bill, it goes back to the house of origin for concurrence. If the two houses cannot agree on one version of the bill, it goes to a committee of conference of both houses for a compromise agreement and re-referral to both houses. *If the second house "Nonconcurs", the bill is dead for the session.*

ENROLLMENT AND SIGNING: After the bill passes both houses in the same form, it is enrolled. It is then sent to the printer, it is signed by both Chief Clerks and the Speaker of the Assembly.

THE GOVERNOR: *Point:* Once the bill is accepted by the Governor, he has 6 days, exclusive of Sunday, in which to act on the bill. *Counterpoint:* If he does not act, the bill is enacted into law.

Point: The 6-day time limit for approval or veto does not begin until a member of the Governor's staff signs for the bill. *Counterpoint:* Sometimes, the Chief Clerk may keep a bill at the Governor's request for several days or even weeks if the volume of legislation is heavy.

VETOING A BILL: *Point:* While the legislature is still in session the Governor, should he decide to veto a bill, must send a written veto message to the house of origin within 6 days of receipt of the bill. If he does not do so, the bill becomes law whether he signs it or not. If the legislature is still in session, it can override any veto by a two-thirds vote of both houses. If the legislature does not act upon the veto, the bill dies. There is no provision for mandatory legislative action on a Governor's

veto. COUNTERPOINT: On the other hand, if the legislature adjourns indefinitely, then a bill does not become law if the Governor does not act on it within 6 days. This is called a "Pocket Veto". Appropriation bills may be approved in part and vetoed in part. This is called an "Item Veto".

A LAW IS BORN: If the bill is signed by the Governor or his veto is overridden by the legislature, it is published in the official state paper (Wisconsin State Journal) and unless the bill provides for a different effective date, becomes law the day after publication.

Once passed and signed into law, the bill receives a chapter number and becomes a "session law" or "act" of that particular session. Individual session laws are printed in pamphlet form called "slip laws". They are referred to by number; e.g., Chapter 90, Laws of 1973.

At the conclusion of the session, a volume is prepared by the Secretary of State and indexed by the Revisor of Statutes, containing all the laws and the more important joint resolutions passed or adopted by the legislature. The volume is generally referred to as "The 1973 Session Laws", although the title on the book's cover will be "Laws of Wisconsin 1973". Ultimately, almost all general law is incorporated into the statute books.

SB 185 Chapter 89, Laws of 1973

Because of differences in reimbursements to school districts for the transportation of various types of handicapped persons (at different rates, for example, between physically and mentally handicapped), the legislature last summer asked the Legislative Council to study the question of transportation. A number of bills were being drafted at that time related to the education of handicapped children. At the same time, parents of handicapped children from Milwaukee and Madison testified that there was a need for compulsory school attendance for handicapped children. It was the recommendation of a parent that the bills be combined into one comprehensive bill. A sub-committee of the Education Committee was appointed to draft such a bill with the help of the parents of the handicapped. The comprehensive bill developed was SB 185.

IMPLEMENTATION OF SB 185: School districts may request that requirements of the bill be waived until June 1976 to allow them to find teachers, set up programs, obtain needed space, etc. 1973-74 is viewed as a year of planning for the implementation of SB 185.

If any parent suspects that his child, 3 years or older, has a special educational need, he may contact the school district or multidisciplinary team. If the parent wishes to have the 3-year old child attend school, he has the right to request an appropriate class from the school district, and the school district must provide it.

Compulsory school attendance is required of all 7-16 or 7-18 year olds, depending on the school district. Only children attending public schools are entitled to services under SB 185.

Progress reports and teacher recommendation reports will be confidential unless an appeal is filed with the school board by the parent. Under SB 185, any child may be represented by an advocate during appeal proceedings. The advocate may be any lay person or an attorney.

Wisconsin's Comprehensive Education Law is considered to be among the best in the country with the exception of the funding provisions.

CONFERENCE ON THE RIGHTS OF THE MENTALLY DISABLED

A statewide Conference on the Rights of the Mentally Disabled will be held Sept. 25 and 26 in Wausau at the Hoffman House, Midway Motor Lodge. National and state specialists will discuss various aspects of the rights of the mentally disabled and current information on legislation and litigation, both nationally and in Wisconsin. Write to the Division of Mental Hygiene, Education-Information Section, 1 W. Wilson Street, Madison, WI 53702 for more information and registration forms.

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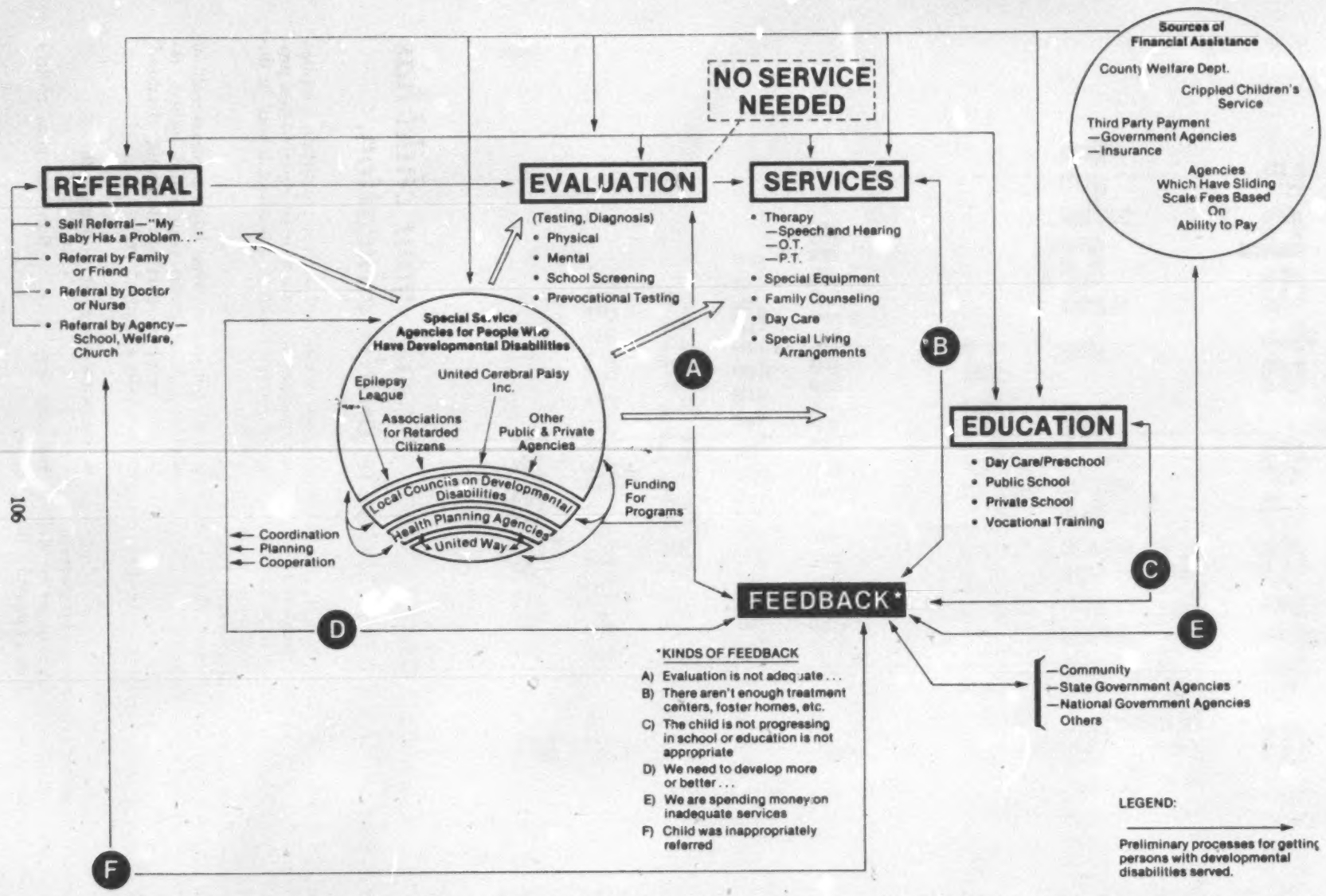

Diagram of System Analysis of the Developmental Disabilities System-Kansas City, Mo.
United Cerebral Palsy Assn. of Greater Kansas City, Inc.
ADVOCACY PROJECT
July, 1975

Take these steps to insure your child's right to education:

1. identification
2. registration
3. evaluation
4. agreement
5. review

"with Liberty and Justice for all," your child has a legal right to an adequate public education.

By law the State of Missouri MUST provide every child with a free, public program of education or training which is appropriate to his or her capacity to learn: "to the maximum extent practicable, handicapped and severely handicapped children shall be educated along with children who do not have handicaps."

"No child may be denied services . . . because of his or her handicapping condition."

"In approving special educational programs for state aid, the Department of Education shall determine that the quality of programming, the supportive staff and services, facilities, supplies and transportation are at least equal to that provided normal children attending school in the district."

It does not matter what label professionals or educators have given your child (gifted, retarded, cerebral palsied, learning disabled, behaviorally disturbed, etc.).

Being on a waiting list is not enough.

And you may have to fight for your child's rights.

1 identification

Although your school district is required—by law—to find and register all "handicapped and severely handicapped children under the age of 21 residing in the district or whose parent or guardian resides in the district":

DON'T count on them.

DO write them. Tell them your child's name, age, birthdate, and type of handicapping condition.

•DO request a **prompt** appointment for testing.

This identifies your child to them. This notifies them of your child's special needs.

Keep one copy and send this letter certified mail. Request return receipt. This is your proof that you sent the letter. EXPECT TO HAVE TO PROVE EVERYTHING. PUT IT ALL IN WRITING. Send one copy to the commissioner of education, Jefferson City, Missouri.

If you wish, send the child advocacy project one copy.

Your address
Date

(Name) School Superintendent
(Name) School District
City, State Zip Code

Dear Sir or Madam:

This is to notify you that our child, (child's name), has been diagnosed as (state your child's disability). He (She) is (age) and was born on (month, day, year) and now requires a program of education and training appropriate to his (her) abilities.

Please arrange to schedule (child's name) for an evaluation as soon as possible.

Sincerely,

SAMPLE LETTER

registration 2

NEXT: Call or visit the school personally and tell them that you want to register your child. Take your child's birth certificate with you. School districts in Missouri also require proof that a child is in a fit bodily condition to attend the public schools. At the school, fill out the registration form, making sure that your child's disability is carefully detailed.

School districts in this state vary in the periods set aside for registration, but you can take your child to the school office **anytime** to register. This step offers another clear method of notifying your school district that you have a child who is not receiving adequate services.

Upon registration of your child, the school should notify you of a time for an appointment for evaluation and placement in a special class or other program.

If you do not hear from your school district by letter or phone —call or write the advocacy project—531-4189.

education and training of children with special needs in Missouri is a right . . . not a privilege.

evaluation 3

After your child has been evaluated (or tested), the superintendent of your school district must inform you of the type of school services which will be offered your child. This information should reach you by certified mail.

If you do not get such information from your school, request that you be given it immediately, in writing, and in detail.

You have a right to understand the placement and what it means to your child. If it is not clear, ask for clarification. Ask people who know your child and have worked with your child. Don't settle for too little.

The Child Advocacy Project will help you with problems in this area. Call us —531-4189.

Remember, you know your child better than anyone else does. If you do not believe that the placement is the best one for your daughter or son, do something about it.

You have a right to:
—inspect and CORRECT your child's records.
—consult YOUR experts.

4 agreement

If you agree with the placement, you need do no more. Be sure you agree. If you don't request a hearing within ten days after you're informed (by certified mail) of the placement, you forfeit the right to a hearing.

If you agree, but later find that the placement is not in your child's best interest, you may be precluded from having a hearing. So be sure you understand the placement and really believe it best.

If you disagree, if you believe your child would benefit more from a different type of service, let your school district know what you would like. Request a hearing by certified mail, return receipt requested, immediately. If you disagree, send a letter to the school and tell them that you want a hearing because you don't feel that your child is being placed in the right class and/or training program. A sample letter, which you may copy, is printed here. The law GUARANTEES a parent the right to a hearing if he or she believes his or her child is receiving inadequate or inappropriate services.

If a child is labeled "handicapped," a parent may pursue his or her rights through the school, then to the school board and then through the courts.

If a child is considered "severely handicapped" a parent would pursue his or her rights through the school, the commissioner of education (in Jefferson City) and then through the courts.

Send the letter requesting the hearing to the school by certified mail with a return receipt. Keep a copy of the letter.

The right to a hearing on your child's status is an important right. The law will only work if you make it work.

If you need help at any point contact the child advocacy project. The project can help guide you through this step. The project may advise you to engage legal counsel to protect your child's interests.

During the review process, time is limited and it is important that a proper record be made. An attorney should insure that that happens.

This letter may be used, with appropriate adjustments, to request a hearing into any aspect of your child's status with which you may disagree.

Send one copy of this letter to the Commissioner of Education in Jefferson City.

Send the letter certified mail with a return receipt requested. Keep one copy for yourself as proof that the letter was sent. Keep the signed receipt when you receive it from the school. This is proof that they received your letter. Expect to have to prove everything. You may send a copy to the advocacy project.

Your address
Date

(Name) School Superintendent
(Name) School District
City, State Zip Code

Dear Sir or Madam:

This is to advise you that we, the parents of (your child's name), do not agree with your planned placement of our child in the program you have outlined for him (her).

We, therefore, in accordance with law, request a hearing on the placement of our child. Would you please notify us as to the time and place of this hearing within the specified time limit.

Sincerely,

SAMPLE LETTER

5 review

When you have requested a hearing, ask to see **All** of the school records on your child (test scores, teachers' reports, and any other information). You have the right to see your child's records at any time.

The school should notify you of the day and time for the hearing. The hearing is usually held at a place near your home, at a time when you are able to attend. It must be held within 30 days of their receiving written request. It is wise to take witnesses with you; ask for the support of people who know your child, such as doctors, social workers or teachers. It would be to your advantage to have a lawyer with you to give you legal advice in the hearing.

You should remember at this point that any testimony given by school officials must be based on an actual examination of your child. Too often schools rely on second-hand information in formulating their decisions.

While a final decision rests with the school board, you should work to protect your child in a hearing by having your own expert testimony available. If this hearing does not satisfy your concerns, you still have the option of a formal hearing or going to court—depending on how your child is labeled. If you need additional help, call or write the child advocacy project. The project can help guide you through the complexities of the review and may recommend legal counsel to insure your rights.

if your school district says "NO!" . . .

If you apply for an education and/or training program for your child, and the school district gives you any reason for not placing your child in class or an alternative program, you have the right to ask for a hearing. Your child's right to a free public education has been violated! Do not accept any of the following reasons for not placing your child in an appropriate program for education and/or training:

1. There are no classes for handicapped children.
2. There is no room in class to accept your child.
3. Handicapped children are not accepted until they reach age 7 years.
4. There are no junior or senior high classes for handicapped children.
5. Handicapped children who are not toilet trained are not accepted into classes.
6. Children with behavior problems are not accepted into classes.
7. There are no facilities for children who cannot walk.
8. There is no money for classes for children with special needs.
9. We can put your child on a waiting list.
10. We will let you know when there is an opening for your child.
11. Your child can no longer benefit from any education or training.
12. We make no provision for home teaching for handicapped children.

None of those reasons is sufficient to deny your child a rightful place in an education and/or training program. If your school district gives any of these reasons for not placing your child . . . contact the child advocacy project immediately.

Call (816) 531-4189 or write:

Child Advocacy Project
3914 Washington Street
Kansas City, Missouri 64111

All children have the same right to an education.

All Children!

Prepared by the Citizen Advocacy Office, 8000 East 63rd Street, Raytown, Missouri 64133.

Appendix P

UCPA ADVOCATE

Vol.1 No.6 OCTOBER 1975

TASK FORCES-WORK

UCPA Advocacy Project Task Forces are at work now trying to gain information about the community and share with others ideas about improving attitudes toward and services for persons with developmental disabilities. The INFORMATION/AWARENESS Task Force staged its first awareness creating activity on Sept.19 at KMBC-TV9 studios. Dennis Allen of Laugh-In repute videotaped a Public Service Announcement (PSA) reviewing some myths about mental retardation and informing people of how to get the FACTS. Many thanks to the Task Force members-especially Matt Davison (JCARC Citizen Advocacy Project). The HOME HELP SERVICES Task Force wants to know if you need help at home with a child who has a disability! What would help you, PARENTS? After surveying several parents, the Task Force finds that parents would be helped best if someone would come into the home for an hour or two each week to work with, stimulate and otherwise occupy the time of their disabled children. Doris Weber, Task Force Chairperson would like to hear about your special needs-call 531-0242 with suggestions. A fact finding meeting with representatives of Missouri and Kansas Offices of VOCATIONAL REHABILITATION was held on September 11 by the EDUCATION Task Force. A highlight of that meeting was a suggestion by VR representatives that parents form coalitions of people concerned about all disabilities to try to influence legislation and service development.

-PARENTS SPEAK OUT-

Results of questionnaires sent to people who attended the Parent Workshop on Rights to Education indicate that many parents want more information about I.Q. testing, evaluation, and issues surrounding these areas from Fred Girardeau of the Children's Rehabilitation Unit of K.U. Medical Center. Parents feel that perhaps program decisions based on I.Q. scores alone are inadequate, unrealistic and most restrictive to children. ...how would you feel if your seat at a football game depended on your score on an electrical wiring test...

FLASH! PUBLIC HEARING! A public on the proposed special education plan for the State of KANSAS is scheduled for October 7, 1975 at 1:30 p.m. in the Board Room of the State Department of Education, Topeka, Kansas. If you need information or want to see the plan, call UCPA Advocacy Project Office 531-0242!

RIGHTS

A member of the local UCPA Board of Directors submitted this article to the UCPA ADVOCATE:

Disabled people and their advocates should familiarize themselves with the new KANSAS CONSUMER PROTECTION LAW which protects citizens from deceptive or dishonest sales practices. The law also says that people who buy products from door-to-door salespeople must be given three days in which to change their minds about buying certain goods. According to the law, advertisers cannot make false statements about products or lie to people about how a product will help them. Another part of the law says that salespeople cannot take advantage of people who are not feeling well or who have handicaps. Finally, the act requires that salespeople make sure that customers understand what they are required to pay when they buy something. Salespeople cannot take advantage of other people who do not understand the terms of a sales agreement. To get more info. about the Consumer Protection Act, call your county or District Attorney in Kansas or write to the Consumer Protection Division Office of Attorney General, State Capitol, Topeka, Kansas 66612.

WHAT'S IN A NAME???

The Kansas City Regional Diagnostic Clinic has exchanged its long handle for another one which is assigned to emphasize the expanded role of the centers. The new name is: KANSAS CITY REGIONAL CENTER FOR DEVELOPMENTALLY DISABLED. And congratulations to J.D. Walker who has been transformed from an administrator to a DIRECTOR!

NEWS FROM THE U.S. DEPARTMENT OF HEALTH, EDUCATION AND WELFARE

As a result of reorganization at HEW, the Developmental Disability Office (DDO) is now directly under the Assistant Sec'y for Human Development. DDO, a coordinating agency is headed by Francis X. Lynch. These facts may come in handy if you're interested in developing grants or improving services for and with persons who have developmental disabilities.

UCPA ADVOCATE is brought to you by the Child Advocacy Project of UCPA of Greater Kansas City, Inc. Project Coordinator, Georgeann Chaffee.

Good Books

"It is discouraging to be told, after your child has been diagnosed and found to be in need of special services, that your local school system is unable to provide the program he needs. But if this happens to you, don't give up. There are steps you can take." p.8. The National Information Center for the Handicapped gives Practical Advice for Parents. This booklet helps you find and evaluate programming for children; tells how to get information from professionals and why joining a parent group may be helpful. Available free from The National Information Center for the Handicapped/ P.O. Box 1492/ Washington, D.C. 20013, the booklet is written so a parent can understand it!!!

Are you college bound? Do you know a person who has a handicap but wants to go to college? Most colleges require applicants to have passed college entrance exams. Special testing programs are available. Write for the booklet: COLLEGE BOARD ADMISSIONS TESTING PROGRAM FOR HANDICAPPED STUDENTS- The address is:

ATP for Handicapped Students
College Entrance Examination Board
Box 592
Princeton, New Jersey 08540

Both of the above are from the Report from Closer Look-National Info. Center for the Handicapped.

LET'S HAVE WELL CHILDREN!

Did you know that about 1,000 children between the ages of 2 months and 6 years are seen each month in Well Child Clincs operated by the K.C.,Mo. Health Department at 17 locations. If you'd like your child to be one of them, call 274-1591 for an appointment at the clinic nearest to your home. And a reminder:

CHILDREN NEED TO RECEIVE A SERIES OF IMMUNIZATIONS BEFORE STARTING TO SCHOOL-FOR THEIR OWN PROTECTION. Call the Well Child Clinics for free immunizations for preschool children-274-1591.

And speaking of Public Health, a review of developmental screening for Public Health Nurses in the K.C.; Mo. Well Child Clinics will take place at an all-day workshop in late October. Another service to the community.

LEGISLATIVE FOLLOW UP

According to letters from local Senators and Representatives to U.S. Congress no action has been taken yet on H.R. 7217/S.6-the Developmental Disabilities bills passed by both houses this summer. It will help if you write to your U.S. Representatives and Senators to ask for their support to ensure passage of an adequately funded act which will meet the needs of persons with developmental disabilities. If you need help with a letter, call: UCPA ADVOCACY PROJECT OFFICE 531-0242

UCPA ADVOCATE
United Cerebral Palsy Association of Greater Kansas City, Inc.
3914 Washington St.
Kansas City, Missouri 64111

Appendix Q

UCP of Rhode Island

PROGRAM COMPONENT PLAN FOR THE ADVOCACY PROJECT

1. Legislative/Governmental Activities
2. Systems Analysis
3. Stimulating Community program development relative to three target populations:
   a. Unserved populations among minority ethnic groups
   b. State institutions
   c. Teenagers and young adults having Community service problems, i.e. SSI and DVR.
4. Case and class advocacy as identified by Project RUSH (Resource Utilization Services for the Handicapped)
5. Organization of consumer action groups

Replication of the San Mateo-Santa Clara Model

1. Processes by which an environment is created to form consumer oriented action groups.
2. Processes by which data is gathered and disseminated to key providers of service and key consumer groups for action.
3. Processes by which a support network is created.
4. Processes by which all voluntary leaders of the affiliate become more active in the advocacy approach.
5. Processes by which forums or arenas are created for consumer/provider communication.
6. Processes by which advocacy approach is integrated into the existing operation of the affiliate.
7. Processes by which specific programs are developed for specific target groups.

In addition, replication from the New York State component—processes by which local and state advocacy councils can make contributions to the affiliate's legislative activities.

The Administrative supervision for the advocacy coodinator will be done by the Program Director of the affiliate.

On-Going Affiliate Operations

The affiliate will also be conducting two other programs which have the following components:

1. UCP program development
   a. Recreation and leisure time activities for children and adults.
   b. Adult education and work activities.
   c. Public and professional educational symposia.
   d. Undergraduate and graduate student internship in the areas of case management, information, referral and follow-along.
   e. Coordination of transportation services.
2. Project RUSH (Resource Utilization Services for the Handicapped)
   a. Case management and case coordination
   b. Client registry
   c. Consumer education related to the Rights Handbook
   d. Continuing data collection
   e. Case finding
   f. Information, referral and follow-along

Appendix R

UCP of Illinois

PROGRAM COMPONENT PLAN FOR THE ADVOCACY PROJECT

1. Program brokerage (where there are difficulties in establishing programs due to the barriers within existing service delivery systems).

2. Organizing consumer groups for action within the legislative program of the state affiliate.

3. Conducting consumer education programs.

4. Expanding the advocacy role of the Mobile Team staff members.

5. Conducting systems analysis for use in monitoring legislative mandates, implementing community organization strategies, etc.

Replication of the New York State Model

1. Processes by which the advocacy project was integrated into the state affiliate's operation.

2. Processes by which the state and local advocacy councils were established.

3. Processes by which local and state advocacy councils made contributions to the state affiliate's legislative activities.

4. Processes by which technical assistance was given to local affiliates in those situations where the development or expansion of programs required a program broker.

5. Processes by which programs are established in areas that are affiliated but lack services in specific areas. (This will be similar to processes by which programs were established in the unaffiliated areas of New York State. The eight affiliated areas cover the entire state of Illinois.)

6. Processes by which deinstitutionalization was fostered.

7. Processes by which the advocacy role of the Mobile Team members (similar role to New York State Home Service Director) were developed or expanded.

On-Going Affiliate Operation

The affiliate will also be conducting the following programs:

1. Legislative development and monitoring.
2. Conducting symposia concerning service delivery for persons with cerebral palsy and related developmental disabilities.
3. Mobile Team programs in five designated areas of the state.
4. Technical assistance to local affiliated areas relative to organizational development and program development.
5. Conducting specific surveys on the unmet needs of UCP consumers.
6. Representing UCP affiliates in Illinois for working with governmental bodies and coalitions within the private sector.

60 THE DENVER POST Tues., Sept. 24, 1974

MAKING IT ON THEIR OWN

By SHARON SHERMAN
Denver Post Staff Writer

One day last week Jeanne Moritzy offered a guest a glass of lemonade.

Eleanor Marks laughingly ordered a friend out of her apartment because he teased her about the biscuits she made for dinner.

David DeBoer jokingly threatened to dunk his girl friend in the swimming pool.

Of such normal (emphasis normal) everyday, small things, happiness is being woven for six victims of cerebral palsy who recently moved out of a nursing home into two apartments.

In the two weeks since they moved from Galaxie Nursing Home, to 336 Grant St., the handicapped young adults have learned to do for themselves and for each other the routine chores of daily life.

It's a relief, they all agreed, not to have to continually depend for such help on overworked or reluctant nursing-home staff members.

The six are proud of their new-found abilities.

"Sally baked a lemon pie last night," said Eleanor, 27, beaming at her roommate, Sally McGrath, 25, who is the most handicapped of the six.

"I can do practically everything for myself," boasted Eloy Maestas, 28.

The six were delighted to try their hands at household chores most people would like to avoid—sorting laundry, dusting, vacuuming and meal planning.

The chance to live nearly on their own and to learn the skills of daily life was a gift from the United Cerebral Palsy Center of Denver, an agency of the Mile High United Way, and two of its employes.

Dottie Christensen, 26, and Steve Baudoin, 25, volunteered to live with Miss Marks, Miss McGrath, Miss Moritzy, Maestas, DeBoer and Butch Willoughby. The center endorsed the plan and gave Miss Christensen and Baudoin the time to find the apartments and help the six move.

Even with that support and aid from some of their families, the six almost saw their bid for independence die on moving day.

Nursing-home staff members refused to let Miss Christensen and Baudoin help their future roommates pack and move their belongings, according to the two cerebral palsy center counselors. Then a night supervisor of the home called police to ask help in preventing some "kids" and their belongings from being removed.

The police found that the "kids" were all over 18, weren't wards of the state and had a right to live wherever they chose.

Even then all the dragons weren't slain.

Rent on the two apartments was due Sept. 7. Normally the $146 a month which each of the six receives from federal funds would arrive before that date. But the Labor Day holiday caused delays and there was some anxious mailbox watching.

"We ended up paying the rent out of our savings accounts," said Miss Christensen. "But we figured the first month would be a mess, so we aren't worried."

Each of the eight is contributing $100 a month to the rent and food kitty.

As happens in most tough situations, the group has found unexpected friends: Dr. Justin Weiker, who unlike the other doctors involved, believes the move is a good thing for the cerebral palsy victims, and is willing to continue watching over their medical needs; the managers of their apartment building who have been willing to allow such major changes as widening bathroom doors to accommodate wheel chairs.

But if the day comes when the six can boast of the success of their venture, they may have to give some thanks to Sy Fink, the Galaxie administrator who tried to prevent their leaving and who still stubbornly insists the experiment won't work.

For Ellie and the others, Fink is a symbol of all those who would deny them the right to wear the scrapes and bruises of life in the real world.

"We'll show him," said Ellie, flinging clothes into the washer.

"There's no way we're going back," Eloy added.

Appendix T

LEGAL ISSUES IDENTIFIED BY THE NATIONAL CENTER FOR LAW AND THE HANDICAPPED

1. Legal issues surrounding **the right to a publicly supported program of education** suited to the needs of all exceptional children to include:
   a. Inclusion in school for all children
   b. Classification of children
   c. Appropriate educational programming
   d. Appropriate alternative delivery systems
   e. Appropriate use of constitutional due process
2. Legal issues surrounding **the constitutional rights of individuals in residential care facilities,** to include:
   a. Safe and habilitative environment
   b. Lawful wage for services performed
   c. Least restrictive alternative
   d. Appropriate commitment procedures
   e. Conflicts in zoning with community based facilities
   f. Guardianship and protective services
3. Legal issues surrounding the **right to procreate and the right to life after birth** to include:
   a. Sterlization
   b. Marriage
   c. Appropriate and timely medical care, either remedial or life saving
4. Special legal issues surrounding the physically handicapped to include:
   a. Nondiscrimination in employment
   b. Access to public transportation
   c. Architectural barrier free environment
   d. Access to all public accommodations, including hotels, restaurants, transportation, etc.

Appendix U

LEGAL ADVOCACY RESOURCE LIST

CHILD ADVOCACY Report of A National Baseline Study	Alfred J. Kahn Shelia B. Kamerman Brenda C. McGowan	Child Advocacy Research Project Columbia University School of Social Work 622 West 113th St. New York, New York 10025
RIGHT TO EDUCATION	Leopold Lippman I. Ignacy Goldberg	Teachers College Series In Special Education
EDUCATION OF HANDICAPPED CHILDREN (2ND EDITION) NOVEMBER, 1972	Elaine Trudeau	The Council For Exceptional Children 1411 South Jefferson Davis Highway Arlington, Virginia 22202
A CONTINUING SUMMARY OF PENDING AND COMPLETED LITIGATION REGARDING THE EDUCATION OF HANDICAPPED CHILDREN NOVEMBER 30, 1973	Alan Abeson	The Council for Exceptional Children 1920 Association Drive Reston, Virginia 22091
LEGAL GUIDE TO THE RIGHTS OF THE DEVELOPMENTALLY HANDICAPPED (A PROJECT REPORT) JUNE, 1973		Edinboro State College Edinboro, Pennsylvania 16412
ADVOCACY FOR THE LEGAL AND HUMAN RIGHTS OF THE MENTALLY RETARDED JUNE 2, 1972	Robert M. Segal	The University of Michigan Ann Arbor, Michigan
THE RIGHTS OF THE MENTALLY HANDICAPPED JUNE 14-16, 1972		Department of Social and Health Services Office of Developmental Disabilities P.O. Box 1788 Olympia, Washington 98504
AN EXAMINATION OF THE CIVIL RIGHTS OF MENTALLY ILL CHILDREN	Leon H. Ginsberg	Child Welfare/Volume LII Number 1, January, 1973
MEDICINE FACES THE CONSUMER MOVEMENT	Walter J. McNerney	PRISM/SEPTEMBER, 1973
PLANNING FOR SOCIAL CHANGE: DILEMMAS FOR HEALTH PLANNING	John G. Bruhn	AJPH, JULY, 1973, Vol. 63, No. 7

ABROAD IN THE LAND: LEGAL STRATEGIES TO EFFECTUATE THE RIGHTS OF THE PHYSICALLY DISABLED		The Georgetown Law Journal Volume 61:1501
PRESIDENT'S COMMITTEE ON MENTAL RETARDATION, THE MENTALLY DISABLED CITIZEN AND THE LAW	Michael Kindred ed.	1975
THE MENTALLY DISABLED AND THE LAW	Rev. ed S. Brakel & R. Rock eds.	1973
LEGAL RIGHTS OF THE MENTALLY HANDICAPPED	B. Ennis & P. Freidman eds.	1973
THE RIGHTS OF MENTAL PATIENTS	B. Ennis	1973
PRISONERS OF PSYCHIATRY	B. Ennis	1972
LEGAL RIGHTS OF THE DISABLED AND DISADVANTAGED	R. Allen	1969
LEGAL PLANNING FOR THE MENTALLY RETARDED	Kay, Farnham, Karren, Krakel & Diamond	60 Calif. L. Rev. 438 (1972)
SYMPOSIUM ON THE MENTALLY DISABLED AND THE LAW		62 Calif. L. Rev. 671-1068 (1974)
DEVELOPMENTS IN THE LAW — CIVIL COMMITMENT OF THE MENTALLY ILL		87 Harvard L. Rev. 1190-14 (1974)
CONFERENCE ON MENTAL HEALTH AND THE LAW		23 Catholic U.L. Rev. 643-773 (Summer 1974)
SYMPOSIUM: MENTAL ILLNESS, THE LAW AND CIVIL LIBERTIES		13 Santa Clara L. Rev. 367-612 (Spring 1973)
SYMPOSIUM: LEGAL RIGHTS OF THE MENTAL RETARDED		23 Syracuse L. Rev. 991 (1972)

Two periodicals which constantly update the status of court cases in this area are:

— President's Committee on Mental Retardation

— Mental Retardation Clearinghouse Review

Revised: January 14, 1975.

Appendix V

GUIDELINES FOR STAFF SELECTION

1) the ability to work directly with persons in need of specific assistance and to help in finding the necessary resources to meet these needs;

2) assist the client in properly utilizing available resources and to gain all benefits to which he is entitled;

3) ability to work with other agencies for the benefit of individual clients;

4) skill in the organization of consumer groups to assist them in identifying service needs and in implementing action to meet those needs;

5) ability to assist persons from a variety of backgrounds to work towards a common end such as in the National, State and Local Advocacy Advisory Councils;

6) knowledge of community organization and planning;

7) ability to assist in the enhancement of the service roles of other professionals in the community and in the United Cerebral Palsy affiliates;

8) ability to work with state organizations for the advancement of appropriate legislative action;

9) skill in the utilization of public media to contact individuals needing advocacy services. Skill in collaborating with established local action groups with attention to the service needs of disadvantaged and minority groups;

10) experience or training in data collection and dissemination;

11) knowledge, experience or training in interpretation and transmission of data for the purpose of legislative action or review by the national legislative staff;

12) ability to help develop formal techniques to evaluate the effectiveness of the program.

Appendix W

UCPA POLICY ON CONSUMER PARTICIPATION

Adopted April 19, 1975

WHEREAS, "over the past few years both National and many affiliates have moved forthrightly to involve consumers in the association. We have strengthened UCP's advocacy role by encouraging both self-advocacy on the part of the disabled and one-to-one responsibility for the handicapped by more able-bodied persons. We have remodeled UCPA programs and services to meet the growing and changing needs of our adult clientele, encouraged clients to serve on our boards and employed handicapped persons to work in our programs."[1]

WHEREAS, The Executive Committee has recognized the importance of consumer representation and significant consumer representation and significant consumer involvement at decision making levels of UCPA, Inc. and[2]

WHEREAS, there are no persons with cerebral palsy presently on the Executive Committee or adequate representation on the Standing Committees

NOW THEREFORE BE IT RESOLVED, that the National UCPA adopt the following policy:

> That a consumer be elected as a Vice-President of UCPA at the Board of Directors annual meeting in accordance with the by-laws of UCPA which state in Article II, Officers, Sec. 1, Titles—"and such other officers as may be deemed necessary by the members of the Corporation." The nominee to be selected from persons with cerebral palsy active within the organization.

AND BE IT FURTHER RESOLVED, that the policy also include, in accordance with Article VI, Standing Committees and Other Committees, Sec. 1 (a) of the UCPA by-laws, "The President of the Corporation may appoint such other members of the Committees as he shall deem necessary," the President shall, at his or her discretion, appoint at least one volunteer consumer with cerebral palsy to each of the National Standing Committees and Other Committees.

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[1] Affiliate Update — from the Office of the Executive Director, Volume No. 2, January 1975.

[2] Minutes of the meeting of UCPA Executive Commitee — Saturday September 28, 1974, Warwick Hotel, New York, New York

Appendix X

REPORT
CONSUMER ADVOCACY COUNCIL
UCP OF GREATER HARTFORD

By Beverly Jackson, President

In July of 1972, $119,000 was awarded to UCP of Greater Hartford for a three-year project to develop a recreation program and a program of activities of daily living. Most importantly, written into the grant was assusrance that all programs would be based on consumer needs. Since July of 1972, consumers have participated in the planning of all programs sponsored by UCP of Greater Hartford. More than 150 adults attend the weekly programs today.

Consumer involvement in program planning proved to be a very successful innovation. Frequently during program planning sessions, extension of consumerism outside of the agency was discussed. In August of 1973, the program staff of UCP selected half a dozen consumers who had active experience in program planning in the past and formed a committee to discuss the establishment of a consumer council. This ad hoc committee was the birth of our present Consumer Advocacy Council.

The Consumer Council, as it was first named, realized that some consumers of UCP were socially oriented and took part in sports and recreation programs. Other consumers were oriented toward bettering their lifestyles, and others were parents of disabled children. It was not important that the needs of each group were different. The important factor was that the needs were not being met. The Council decided that the service delivery system required change, and that consumers, no matter what their disability, should unite to bring about desired changes.

In September of 1973, the Consumer Council added "Advocacy" to its title and selected four more consumers to round the Council off to ten consumers and one UCP staff person.

The CAC was initially an elite group of disabled adults, of various disabilities (amputee, arthritic, cerebral palsy, muscular dystrophy, paraplegic). These CAC members were emotionally mature; they were concerned but not contentious.

In its second year of existence, the CAC decided to determine membership by election from the cerebral palsied community. Agency staff representation was maintained. The agency recognized the emergence of consumer action as a much needed entity, and the CAC appreciated the supportive services that were provided by the agency such as transportation, stationery, telephone, postage, resource materials, and staff resources.

Also, in 1973, the Board of Directors of United Cerebral Palsy of Greater Hartford, actively recruited consumers to expand their representation on the board, and the president of the CAC, as a standing committee, was made a member.

Consumers broadened their participation from program planning to participation in making policies and establishing procedures of the agency. As the CAC formed committees to work on architectural barriers, housing, legislation, transportation, vocational opportunities, and discrimination, the agency gave whatever support necessary to effect action, but only when it was invited to do so.

This year, the CAC seeks to extend its base deeper into the community of Greater Hartford. Disabled adults served by the agency as well as disabled adults not served by the agency, parents of disabled adults and children, and concerned citizens are being recruited for membership this year. Three goals are to be achieved with this representation:

1. Representatives will be able to watchdog state and federal legislation in each community in Greater Hartford;

2. Twenty-eight advocates, truly representing Greater Hartford will be available to act upon legislation proposals; and

3. The CAC will be recognized by the disabled population, as well as by legislators, as their advocate.

Speaking of action, I'd like to tell you about some of our most successful activities; those of which we are most proud:

ARCHITECTURAL BARRIERS: In 1974, the CAC wanted to demonstrate to Greater Hartford the environmental barriers, attitude and architecture, faced by one in 10 citizens with limited mobility.

Awareness Day was chosen as the medium. Awareness Day is not a creation of the CAC. It has been held by many agencies in many states. Two things are significantly different about our Awareness Day:

1. A consumer group, not an agency, coordinated our Awareness Day. The CAC co-ordinated agencies; and

2. Our Awareness Day exceeded the boundary of Greater Hartford. Six major cities and 20 smaller communities held specific events.

In 1975, the CAC assumed Awareness Day coordination for the entire state of Connecticut. Our Lt. Governor and Secretary of State spent their entire working day in wheelchairs, along with many other local public officials across the state. Governor Ella Grasso issued an official proclamation recognizing Awareness Day.

For 1976, an Awareness Day "How to do it" booklet has been written and the Connecticut JayCees have been enlisted to carry out the project.

Our future goal is to make Awareness Day a National program on May 1st annually.

Awareness Day has resulted in the passage of bills mandating accessibility in 10% of all housing units built with federal or state monies as of October 1, 1975, curb cuts in new or reconstructed sidewalk construction, and the requirement that all buildings built according to

American National Standards Institute specifications must display the international accessibility symbol.

TRANSPORTATION: The CAC wrote letters of support as individuals and as a body to help UCP of Greater Hartford acquire an Urban Mass Transportation Administration grant to provide accessible dial-a-van services for disabled persons in Greater Hartford. Because of our effort, the Greater Hartford affiliate was one of the 13 grant recipients.

LEGISLATION: The experience and expertise of the chairperson of our Legislation Committee has led her to become the consumer representative on Capitol Hill in Hartford for all of the United Cerebral Palsy associations of Connecticut. In a cooperative effort of the Greater Hartford affiliate and the state office, our consumer representative is sent to the state capitol nearly every day of the week while the General Assembly is in session. Her presence reminds legislators of their responsibility to their disabled constituents. Her presence and the contacts she has established has been invaluable to the CAC and disabled individuals.

NATIONAL: My appointment to the UCPA National Advocacy Advisory Council is a direct credit to the CAC.

INTERNAL: The CAC is very proud of the respect given by the agency and board of UCP of Greater Hartford. The staff always includes consumers in program discussions, and the board continually seeks the input of consumers.

As individuals, CAC members hold memberships in other organizations and rehabilitation agencies. Some hold memberships on committees dealing with employment, housing and transportation.

I would like to touch base with some of our greatest problems and how we hope to overcome these problems. Even in our short history, the CAC has had difficulty establishing participation from consumers who are not CAC members. Apathy, poor communication and a lack of understanding about the CAC have been major stumbling blocks. This year we will take a number of steps to overcome these problems:

1. Consumers will be recruited to join committees headed by CAC members;

2. Consumers will be asked to clip newspaper items that would be of particular interest to the CAC. These persons will be given an orientation to the CAC's interests, and UCP of Greater Hartford will purchase subscriptions for these persons when necessary.

3. Consumers will be asked to document stories and activities of the CAC and to maintain a scrapbook.

4. Mailings, typing, folding, etc., will be given to consumers.

5. Research may even be requested of consumers.

Appendix Y

PARENTS FOR IMPROVED COMMUNITY SERVICES

PROPOSED CHANGES IN THE MANNER IN WHICH LOMA PRIETA REGIONAL CENTER SERVES THE DEVELOPMENTALLY DISABLED

Service Philosophy

A. All disabilities eligible for service shall have their requirements met equally, irrespective of the type or severity of the handicap.

B. Loma Prieta shall fulfill its responsibility of preserving and supporting the family unit.

C. An effort shall be made to reach out to those handicapped individuals who, because of past service priorities, were denied access to services.

Policy Making

In order to provide broad community participation, the policy making bodies for Loma Prieta shall have representation drawn from all disabilities entitled to service, with representatives selected from agencies and parent groups.

Public Information

A. Parents, physicians (particularly pediatricians and neurologists), and all people working with handicapped citizens shall receive the following current information in writing:

1. A statement as to who is eligible for Loma Prieta services.
2. A descriptive list of services available to Loma Prieta clients.
3. A time-frame for intake, evaluation, and purchase of service.
4. A concise statement of the right to appeal a denial of eligibility or a denial of specific services to eligible individuals.
5. A discussion of the manner in which "core" staff decides who shall receive particular services and the possible circumstances under which an individual might be denied such services.

B. Changes in operating policy which may affect recipients of Loma Prieta services shall be made known promptly to the general public and interested groups, in writing.

Client Rights

A. Parents shall be entitled to be present and represented at any "family conference" or "staffing" regarding their child and shall be given adequate notice of the time and place of the meeting.

B. Parents shall be given at least two weeks written notice of a decision to terminate any ongoing service purchased by Loma Prieta. This notice shall in-

clude specific reasons for the action and shall describe the procedures which must be followed in order to appeal the decision.

C. Parents shall have unobstructed access to all records pertaining to the family, regardless of the origin or nature of the records, and shall have the right to have any inaccurate or non-pertinent information removed or pertinent material added.

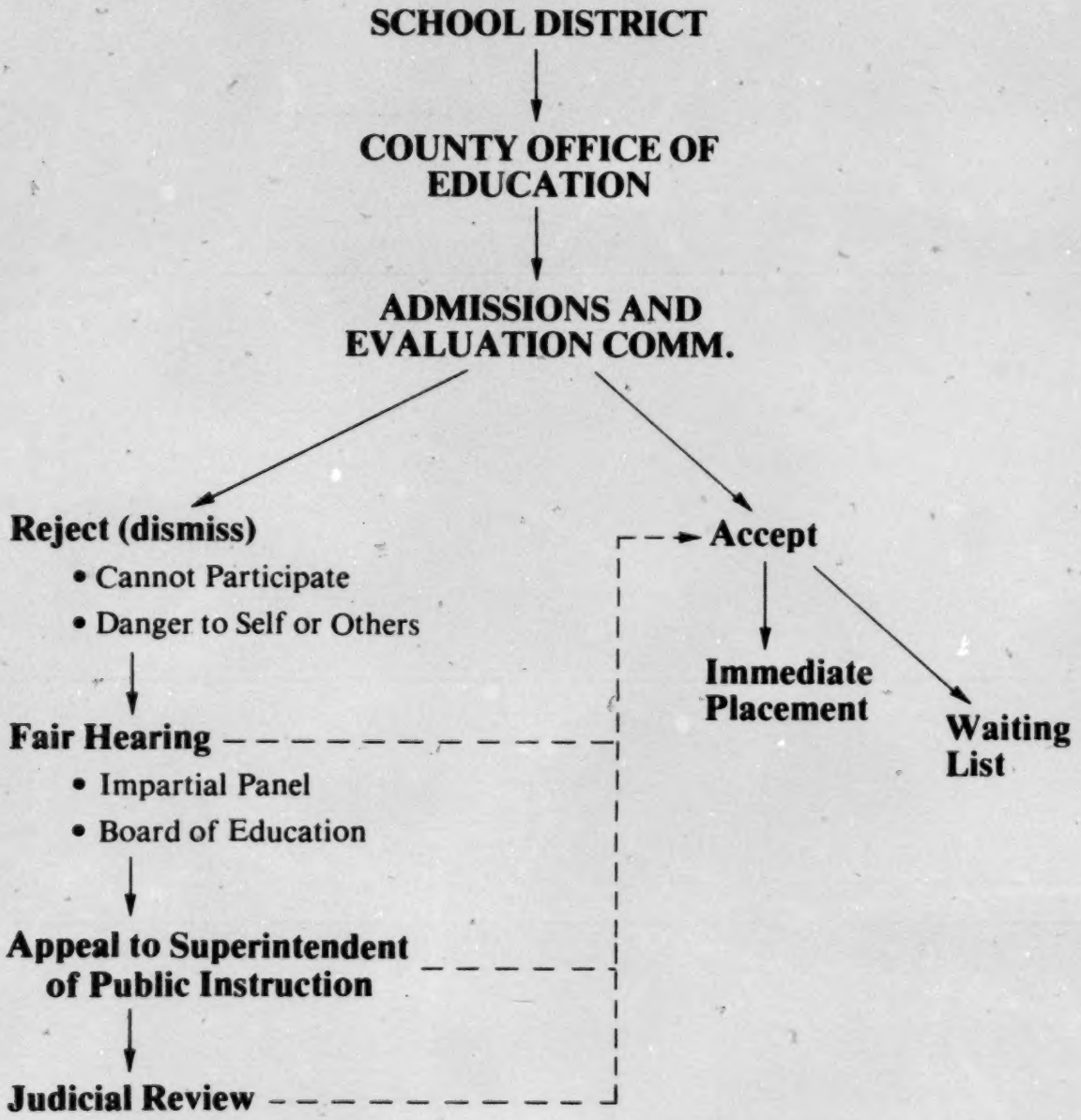
D. The practice of employing pre-signed blank release forms shall be discontinued immediately.

E. Information requested by Loma Prieta from agencies or individuals shall pertain only to the person who is receiving or might receive services and shall, in particular, not concern other members of his or her family, unless the informed consent of those members is first obtained in writing.

DSP:9/11/75

Appendix Z

Placement Process for Development Centers for the Handicapped



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